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# California Traumatic Brain Injury Planning Project

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## Needs and Resource Assessment

*A Traumatic Brain Injury occurred every 20 minutes between 1996 and 1998 in the State of California.*

*The vision of the California Traumatic Brain Injury Planning Project is to generate a practical, outcome-oriented plan for services that meet documented needs and that reflect the concerns and desires of TBI survivors and family members who are struggling to achieve a reasonable quality of life in environments where many basic services [e.g., accessible and affordable housing and transportation] are lacking at present.*

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# **I. Introduction**

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## **I.1. Background**

Congress enacted Public Law 104-166 in 1996 “to provide for the conduct of expanded studies and the establishment of innovative programs with respect to traumatic brain injury”. The Law provides that the Health Resources and Services Administration, Maternal and Child Health Bureau is responsible for implementation of a State Demonstration Grant Program to improve access to health and other services for individuals with traumatic brain injury [TBI] and their families. There are two program categories in the TBI State Demonstration Grant Program: Planning and Implementation. The planning category provides support to those states that need assistance in developing an infrastructure for individuals with TBI and their families. The implementation category supports the development and expansion of activities that will improve or enhance access to services for individuals with TBI and their families, within the current service delivery system.

The California Department of Mental Health was awarded a Traumatic Brain Injury Planning Grant in 1999. The grant requires establishment of Four Core Capacity Components.

- 1) Development of a statewide TBI Advisory Board.
- 2) Designation of a state agency and staff responsible for coordination of state TBI activities.
- 3) Completion of a statewide needs/resource assessment, with an emphasis on resources, of the full spectrum of care and services from initial acute treatment through community reintegration for individuals of all ages having TBI.
- 4) Development of a statewide Action Plan to develop a comprehensive community-based system of care that encompasses physical, psychological, educational, vocational, and social aspects of TBI services and addresses the needs of individuals with TBI and their families.

The purpose of this report is to present the analysis of the statewide needs/resource assessment as required by the third Core Capacity Component. The report has three sections in addition to the Introduction. The first is an analysis of the TBI survivor and family surveys. The second is the needs assessment. The third section is an assessment of resources.

## **I.2. Definition of Traumatic Brain Injury**

TBI [cranio-cerebral head trauma] is defined as *“an occurrence of injury to the head [arising from blunt or penetrating trauma or from acceleration-deceleration forces] that is associated with any of these symptoms or signs attributed to the injury: decreased level of consciousness, amnesia, other neurologic or neuropsychologic abnormalities, skull fracture, diagnosed intracranial lesions, or death.”* The major causes of TBI are motor vehicle crashes, falls, violence and sports injuries.

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## **I.3. Data Sources**

### **I.3.1. Surveys**

Four survey instruments were used to collect information on needs and resources.

- 1)** The Advisory Board developed a six-page TBI survivor survey instrument. The survey was designed to be confidential and did not ask the survivor to identify her/himself. Data elements on the survey relate only to the survivor and include city of residence, age, sex, race/ethnicity, marital status, education, living arrangements, source of financial support, information about the injury, pre and post injury employment, post injury education, everyday activities, transportation, life changes, services and satisfaction, and unmet service needs.
- 2)** The Advisory Board also developed an 11-page family member survey instrument. The survey was designed to be confidential and did not ask for identification of the survivor or the family member completing the survey. There are data elements on the survey that relate to the family member as well as the survivor. The family data elements include city of residence, age, how they are related to the person with TBI, race/ethnicity, marital status, and education. The data elements related to the survivor include race/ethnicity, marital status, education, place of residence, estimates of future need for long term care and assisted living, source of financial support, information about the injury, pre and post injury employment, post injury education, everyday activities, transportation, life changes, concerns about the survivor's future, services and satisfaction, and unmet service needs. The survey also asks questions about the family and survivor's life since the injury. The final section of the survey asks families to rate descriptions of services.
- 3)** Service provider organizations were surveyed using an eight-page instrument developed through the Division of Child, Adolescent and Family Health [DCAFH] of the Maternal and Child Health Bureau of the Health Resources and Services Administration. The survey's data elements include the name and location of the provider, categories of services, funding status of the organization [e.g., public, for profit, non-profit], availability of TBI program/services, county of service, number of TBI individuals served, referral sources for their program, sources of funding for TBI services, staffing, desired training information, service information by category, ratings for brain injury services within their geographic area, needed services, gaps in services in California and referral sources from their program.
- 4)** State and county agencies were surveyed using a 10-page survey instrument developed by DCAFH. The survey asks the agency whether individuals with TBI are eligible for services. If the answer is yes, the survey asks questions regarding the total number of individuals served, the number of individuals with TBI, demographic information about the individuals with TBI, referral sources, time for start of services, staff, services provided by the organization, numbers of individuals with TBI by age receiving services within each category of service, education and training efforts, financial resources, inter-organization participation among agencies that serve individuals with TBI, and gaps in services related to TBI.

The TBI survivor and family surveys were distributed through consumer groups, targeted non-profit and for profit organizations, and selected state agencies serving TBI survivors and their family members. The TBI survivor survey mailing list includes 250 organizations and agencies. The family survey mailing list includes 260 organizations and agencies. DMH distributed 3050 family and survivor surveys. The organizations and agencies had the option of making additional copies of the survivor and family surveys.

The provider survey was distributed through a list of 399 organizations and agencies. Some of the membership organizations on the list sent surveys to their constituencies.

State and local agency surveys were sent to 60 state agencies, 62 county health officers and 59 county mental health directors.

### **I.3.2. Forums**

Nine public forums were held between April 2000 and January 2002. The forums were held in Long Beach, Eureka, Novato, Chico, Sacramento, Fresno, Colton, Bakersfield, and San Diego. The forums were a collaborative undertaking in which DMH co-sponsored the event with various statewide and local organizations, agencies, and service providers. Members of the Advisory Board participated on the panels conducting the forums. Fifty or more people attended each of the forums.

The forums provided an opportunity for TBI survivors, family members and others to participate in the planning process. Participants were encouraged to tell the panel about what was working and what wasn't working, access to services, service gaps, integration and coordination of services, as well as issues of diversity and cultural competence.

### **I.3.3. Focus Groups**

Six focus groups were held in 2000. The focus groups were held in San Jose, Orange County, Santa Cruz, Capitola, Sacramento, and Eureka/Lakefront. The numbers of participants ranged from eight to 33. Participants included survivors, family members, service providers and others.

The purpose of the focus groups was to gather information about the availability, accessibility and usefulness of services to TBI survivors as well as service needs, gaps and barriers. Each focus group had a facilitator who recorded and reported on the responses to four questions.

- 1) Since your head injury, what services have been helpful to you?
- 2) Can you explain why these services have been helpful?
- 3) What other services would you like to have?
- 4) Have any of the services you mentioned not been available to you? If not, can you tell us why?

## II. Analysis of TBI Survivor and Family Surveys

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### II.1. Number of TBI Survivor and Family Surveys Analyzed

Table 1 shows the number of TBI survivor and family surveys that were received and analyzed. Surveys that did not meet the definition for TBI were removed from survivor and family surveys. Two blank survivor surveys and three surveys received from survivors who live in other states were also removed. Survivors filled out six family surveys. These surveys were included in the analysis of survivor surveys.

Table 1		
	Survivor Survey	Family Survey
Total surveys received	617	155
Blank surveys	-2	-1
Reallocation of family surveys filled out by survivors	6	-6
Did not meet the definition of TBI	-29	-30
Survivor lives out of state	-3	
Total surveys analyzed	589	118

### II.2. Demographic Comparisons

The survivor and family surveys collected demographic information about the survivors. Both surveys collected information on race/ethnicity, marital status, and education of the survivor. The survivor survey also collected information on the age and gender of the survivor.

#### II.2.1. Age and Sex

Table 2 compares the survey information on age and sex of the survivors with 1998 Statewide TBI Surveillance data for non-fatal injuries. The surveillance age data had to be regrouped in order to make the comparison. The regrouping is based on the assumption that the ages are spread evenly within each of the age categories.

As shown on Table 2, almost half of the surveillance group were in the under 18 [23%] or 60 and over [26%] age groups. Only 10 percent of the survivors in the survey data were in these age groups with 1 percent in the under 18 and 9 percent in the 60 and over age groups. Exploring the needs of individuals in these two age groups could be addressed in future planning efforts.

Sixty-five percent of the surveys were for survivors between the ages of 36 and 59-years. This age distribution is reflected in the 43-year-old median age for the survivors. The 35-year-old median age for the surveillance data is reflective of the greater proportion of individuals under 18 and 60 and over age groups.



There is no difference in the proportion of males and females in the survey and surveillance data. Two-thirds of each group was male.

Age and Sex	Table 2			
	TBI Survivor Surveys		TBI Surveillance Data	
	Number	Percent	Number	Percent
Total	588	100%	22,711	100%
Age				
<18	5	1%	5316	23%
18-21	25	4%	1653	7%
22-35	112	19%	4388	19%
36-45	195	33%	3002	13%
46-59	189	32%	2531	11%
60 +	55	9%	5821	26%
Sex				
Female		33%	7712	34%
Male		64%	14999	66%
Unknown		3%		

## II.2.2. Race and Ethnicity

The TBI survivor and family surveys include information on race and ethnicity for survivors. Table 3 compares the survey information to the 2000 population for California as reported by the California Department of Finance.

Race and Ethnicity	Table 3			
	Survivor/Family Surveys		California 2000 Population	
	Number	Percent	Number	Percent
Total	703	100%	33,871,348	100%
White/Caucasian	528	75%	15,816,790	47%
Hispanic/Latino	79	11%	10,966,556	32%
Asian/Pacific Islander	29	4%	3,752,596	11%
African American	10	1%	2,181,926	7%
American Indian	22	3%	178,984	1%
Multi-racial	22	3%	903,115	3%
Other/Unknown	2	0%	71,681	0%
Unknown	11	2%		

The comparison shows that the survivors are not like the general population in California. The data shows 47 percent of the general population as White persons not of Hispanic/Latino origin. The survey data shows 75 percent of the survivors classified themselves as White/Caucasian. Exploring the needs of other racial and ethnic populations could be addressed in future planning efforts.

### II.2.3. Education and Marital Status

Table 4 compares the educational attainment of the survivors to the educational attainment of persons 18 and older in the California 1990 Census. The data is not available for the 2000 Census at this time. The comparison shows that the survivors are better educated than the general population.

<b>Table 4</b>			
<b>Educational Attainment</b>	<b>Survivor/Family Surveys</b>		<b>Educational Attainment Persons 18 years and Older 1990 Census</b>
	<b>Number</b>	<b>Percent</b>	
Total	703	100%	
11 <sup>th</sup> grade or less	96	14%	25%
High school diploma	276	39%	23%
G.E.D.	44	6%	Included above
Vocational	46	6%	Not reported
AA degree	77	11%	8%
Bachelors degree	95	13%	14%
Graduate degree	57	8%	7%
Unknown	15	2%	

No general population comparison was found for marital status. It is interesting that 51 percent of the survivor and family surveys indicated that the survivor was "Single, never been married". When marital status is compared to age groups in survivor surveys, the "Single, never been married" category was checked for the majority of persons in each age group through ages 36 to 45. Twenty-eight percent of the survivors ages 46 to 59 and 13 percent of the group 60 and older also indicated that they were "Single, never been married".

Twenty-two percent of the survivors were either divorced or separated. Twenty-three percent were married or living with a significant other.

### II.3. Injury Information

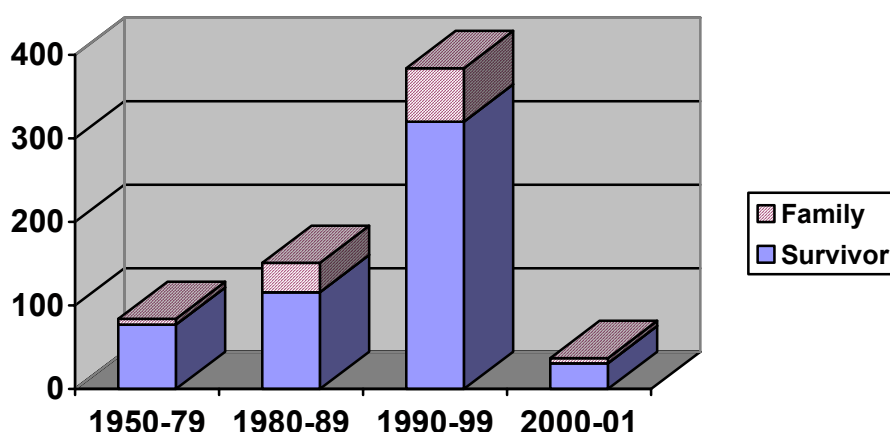
The surveys asked when the injury occurred, the age at the time of the injury, the cause of the injury, whether the person lost consciousness and whether drugs and alcohol were involved in the

injury. The family survey asked for more specific information on the use of drugs and alcohol related to the injury. The family survey asked whether either or both parties had used alcohol or drugs.

### II.3.1. Year of Injury

The survivor and family surveys report injuries that occurred over a 50-year span. The earliest reported injury was 1950 and the most recent injury was 2001. Chart 1 shows the date of injury for the survivor and family surveys. Almost 60 percent of the injuries happened after 1990. Forty-one percent happened between 1995 and 2001. This is advantageous for the needs assessment. Many of the survivors and families will have recent experience getting through the first five years of the post acute phase of the injury. Their experience should be valuable in identifying strengths and weaknesses in the service delivery system.

**Chart 1: Year of Injury**

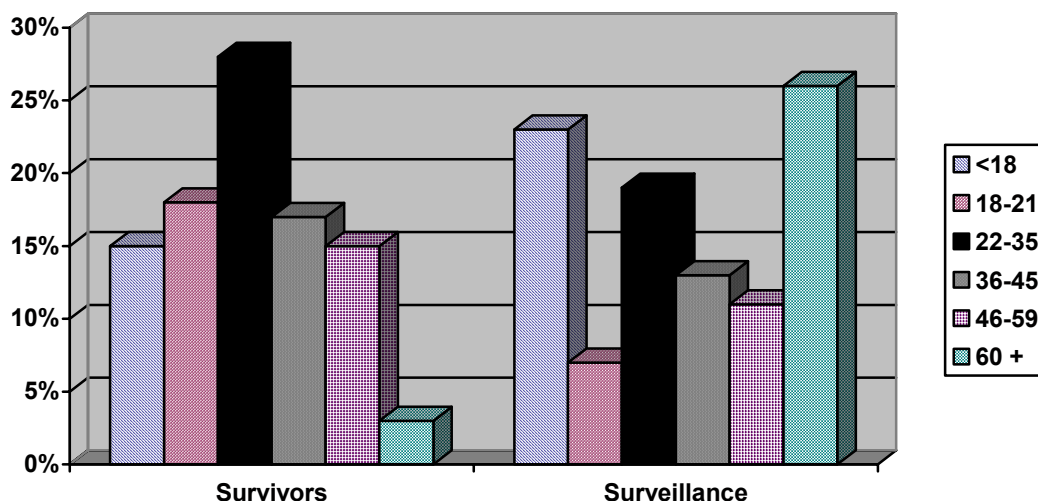


### II.3.2. Age at Injury

The current age of the survivors was compared to 1998 TBI surveillance data for non-fatal injuries in a previous section of the report. That comparison found significant differences in the pattern of distribution among age categories between the two groups. Chart 2 compares the age at the time of injury for survivors with the 1998 surveillance data for non-fatal injuries.

As shown on Chart 2, there are differences in the pattern of distribution among age categories between the two groups. The most significant difference is in the proportion of injuries to people age 60-years and older. In the surveillance data 1 in 4.3 injuries happened to a person who was age 60-years or older as compared to 1 in 37 injuries among survivors. The concentration of injuries among the under 18 and 60-year and older group in the surveillance group is evident in the 35-years old median age for the group. The median age for the survivor group at the time of the injury is 30-years which is reflective of the small number of survivors in the 60-year and older group. An additional factor in the 30-years median age is the concentration of survivors in the age group between 22 and 35.

**Chart 2: Age at Injury**



### II.3.3. Cause of Injury

The surveys reported how the injury occurred. The categories include automobile crash, motorcycle crash, all-terrain vehicle, bicycle crash, other vehicle, vehicle hit pedestrian, vehicle hit bicycle, gunshot wound, assault/abuse, fall, water accidents, sports injury, other and don't know. The categories were regrouped into six summary categories contained in the surveillance data report for purposes of comparison. The numbers in parentheses are the injuries reported in the surveys.

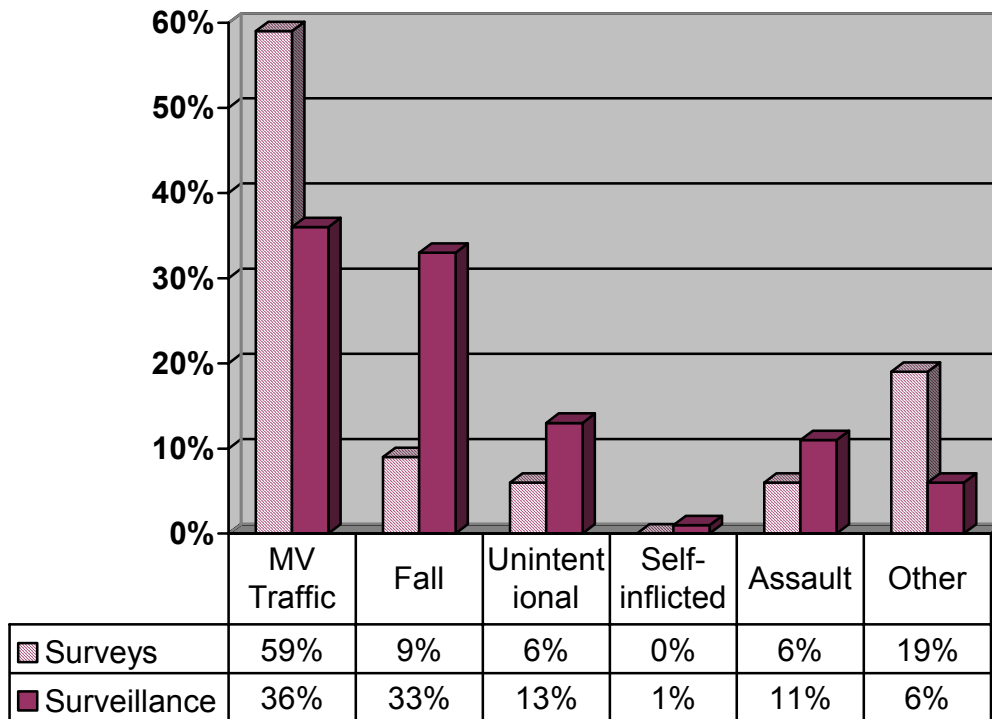
- 1) Motor vehicle traffic includes automobile crash [279], motorcycle crash [75], all-terrain vehicle [3], other vehicle [13], vehicle hit pedestrian [29] and vehicle hit bicyclist [12].
- 2) Fall [67] is a separate category on the survey and surveillance summary.
- 3) Other unintentional includes bicycle crash [20], water accidents [6], and sports [19]
- 4) The surveys did not report any injuries in the intentional self-afflicted category.
- 5) Intentional assault includes assault/abuse [33] and gunshot [12].
- 6) Undetermined other includes other [112], don't know [14], and unstated [9].

Chart 3 compares the causes of injury reported on the surveys and the surveillance data. The causes of injury reported on the survey data is very different than the causes of injury reported on the surveillance data. One possible explanation for the differences is the large proportion of injuries in the "Other" category for the surveys. In most cases survivors and families who chose the "Other" category did not explain the injury.

Injuries caused by motor vehicle traffic accidents and falls were the areas where there was the greatest disparity between the surveys and surveillance data. Motor vehicle traffic accidents were the cause of 1 in 1.7 injuries among the surveys as compared to 1 in 2.7

injuries reported on the surveillance data. There were many more falls in the surveillance data [33%] than the survey data [9%]. The larger number of people 60-years and older in the surveillance data may explain the difference in the incidence of falls.

**Chart 3 Cause of Injury**



### **II.3.4. Other Information about the Injury**

The survivor and family surveys asked whether the person lost consciousness and for how long, and whether alcohol and drugs were involved in the injury. Table 5 shows the detail for the injuries reported on the surveys. The number of injuries in each category orders the table. The percentages are for the total number in each column.

- Alcohol and/or drugs were involved in 21 percent of the injuries. Alcohol and drugs were a factor in automobile crashes, motorcycle crashes and falls.
- Ninety-one percent of the injuries resulted in a loss of consciousness with 58 percent lasting more than 74 hours.
- More people [40%] were injured in automobile accidents than any other category. Seventy-one percent of the survivors injured in automobile accidents were unconscious for more than 74 hours with 42 percent being unconscious for more than 3 weeks. Alcohol and drugs were a factor in 27 percent of automobile crashes. In fact, automobile crashes account for 52 percent of all alcohol and drug involvement reported on the surveys.

- Alcohol and drugs were also a significant factor in motorcycle crashes. Thirty-three percent of the motorcycle accidents involved alcohol and drugs. Seventy-two percent of the survivors of motorcycle accidents were unconscious for 74 hours or more with 43 percent being unconscious for more than 3 weeks.

Cause of Injury	Total	Table 5 Lost Consciousness							Alcohol/ Drugs
		No	<20 min.	20 min. - 24 hr.	24-72 hrs.	74 hr. 3 wk.	Over 3 wk.	Don't know	
Total	707	67	34	26	42	168	243	127	146
Percent total	100%	9%	5%	4%	6%	24%	34%	18%	21%
Automobile crash	283	10	11	7	17	81	120	37	76
Other	112	29	8	5	4	17	28	21	5
Motorcycle crash	75	3	1	4	3	22	32	10	25
Fall	67	8	5	5	6	12	15	16	13
Assault/abuse	33	2			6	5	9	11	9
Vehicle/pedestrian	29	2	2		2	5	12	6	8
Sports injury	25	3	3	2		7	6	4	3
Don't know	23	4	2		2	2	2	11	1
Bicycle crash	20			2	1	6	6	5	
Other vehicle	13	2	1		1	2	4	3	4
Vehicle/bicycle	12	1	1			5	3	2	
Gunshot wound	12	3		1		2	5	1	2
All terrain vehicle	3					2	1		

## II.4. Injuries by County

Appendix 1 compares the county of residence of the survivors as reported on the surveys with the 1998 surveillance data for brain injuries by county of residence. The purpose of the comparison is to give a rough indication of how representative the surveys are with respect to geographic distribution of injuries. It is acknowledged that the survivors may currently live in a county that is different than the one where the injury occurred.

A total of 657 survivors are included in the comparison. The family survey did not ask for information on the city of residence for the survivor. However, 65 survivors live with the person

who filled out the survey and are included in the 657 total. There are differences in the geographic distribution between the surveys and the surveillance data.

- Half of the injuries reported in the surveillance data occurred in Los Angeles [26%], San Diego [11%], Orange [8%], Alameda [5%] and Riverside [5%] Counties.
- Half of the survivors resided in Orange [20%], Los Angeles [16%], Santa Clara [10%] and Santa Cruz [8%] Counties.

The differences are likely attributable to the method of distribution of the surveys. Geographic distribution of survivors is an area that could be explored in future planning efforts.

## **II.5. Life After the Injury**

The survivor and family surveys include information about the survivors' life after the injury. There are questions related to living arrangement, employment, educational attainment, source of income, relationships and ability to perform activities of daily living.

### **II.5.1. Living Arrangements**

Information on living arrangements includes members of the household, the kind of living arrangement and whether the person was satisfied with the living arrangement. The family survey asked whether the survivor would benefit from assisted living or long term care. Appendix 2 contains a table that details the living arrangement information.

#### **II.5.1.1. Members of the household**

The survivor survey asked the survivor to list members of his/her household. The survey listed eight options: alone; spouse/partner; parents; other relatives; children less than 21; friends/roommates/housemates [not relatives]; personal care attendant or home aide; and other. Survivors were asked to check all the options that applied to their situation. The family survey asked whether the survivor lived with the person filling out the survey. If the answer was "no" then the survey asked the person to indicate all the options that applied to the survivor. Not surprisingly there are many variations in households. Appendix 2 lists all of the variations. Some of the interesting findings about the survivors' household are summarized below.

- Twenty percent [142] of the survivors lived alone.
- Of the remaining survivors, 60 percent lived with one other choice.
  - Seventeen percent [123] of the survivors lived with a spouse/partner.
  - Twenty-three percent [162] lived with their parent[s]. Another 5 percent [33] lived in households that included a parent and other people.
  - Other choices included 66 [9%] lived with friends/roommates/housemates; 29 [4%] lived with a personal aide; 23 [3%] lived with another relative; and 18 [3%] lived with children under 21.

- A total of 163 [23%] survivors lived in a household that included a spouse/partner.
- A total of 195 [28%] survivors lived in a household that included a parent.
- A total of 67 [9%] survivors lived in a household that included children under 21.
- A total of 84 [12%] survivors lived in a household that included a friend/roommate/ housemate.

#### **II.5.1.2. Age of parents**

The large number of survivors who live with their parents gives rise to concerns over the age of the parents. There are 195 survivors who live in a household that includes a parent. Of these, 157 were reported on survivor surveys and 38 were reported on family surveys.

- The survivor surveys do not include the age of the parents. The age of the survivor is an indication of the age of the parent. Eighty-two of the survivors who lived with their parents were 36-years or older. The parents of these survivors are probably 60-years or older.
- The family survey does not contain information on the survivor's age but does list the ages of the respondents. There were 16 parents who were 60 to 70-years old and two parents who were over 71.

The needs of aging parents could be explored in future planning efforts.

#### **II.5.1.3. Type of living arrangement**

Appendix 2 shows the living arrangement for each of the households. Given the large number of survivors who either lived with a parent or alone, it is not surprising that 83 percent lived in private residences. The remaining 17 percent was spread across the other options with the largest number of survivors living in group homes [6%] or nursing homes [5%].

#### **II.5.1.4. Satisfaction with living arrangements**

Overall, 520 of the surveys indicated satisfaction with the living arrangement. Eighty-eight percent of the satisfaction was expressed by or for survivors who lived in private residences. The lowest rate of satisfaction by living type was the five survivors who lived "Here and There" or in "Hotel/Motel" living arrangements. As will be seen in the later portions of this report, there is a disparity between the satisfaction expressed on the surveys and the recurring theme that affordable housing options are needed.

#### **II.5.1.5. Need for assisted living and long term care**

The family survey asked questions regarding the survivor's risk of being put in a long term care facility if her/his current living arrangement changed. Thirty-five family members said yes to this question. They were not asked to give details regarding the



reason. Twenty-one of the 35 families indicated satisfaction with the current living arrangement.

It is interesting that two of the 35 survivors lived in nursing homes, which are considered long-term care options. The other 33 survivors lived in a wide range of options including with parents [10], in group homes [9], with spouse/partners [5], alone [4], with a personal aide [2], with friends/roommates/housemates [2], and with his/her son [1].

A second question asked whether the family member would benefit from an assisted living situation and the kinds of assistance that would be needed. Forty-nine family members indicated that the survivor would benefit from assisted living. Twenty-five of the family members also indicated that the survivor was at risk of being put in a long term care facility.

Specific assisted living needs identified on 39 surveys are summarized in Table 6. It should be noted that in some cases the surveys identified more than one need.

<b>Table 6</b>	
<b>Need</b>	<b>Number</b>
Assistance with activities of daily living	16
Supervision	13
Housekeeping, meal preparation, other independent living skills	8
Total care or assistance	5
Social/recreation activities	5
Companionship and encouragement	5
Financial and money management	5
Learning and therapies	4
Health and medical	3
Transportation	3
Structured day program or work	2
IHSS/in home assistance	2
Transitional living	1
Futures planning	1

## **II.5.2. Post Injury Employment**

The surveys asked questions regarding the survivor's current employment status, past employment status, and reasons the person was not currently working for pay.

### **I.5.2.1. Current employment status**

The current employment questions asked what the survivor's work situation was over the past month. There were four options: full time, part time, volunteer and not working for

pay or volunteering. Table 7 summarizes the employment information and adds two other options: under 18-years and retired.

As shown on Table 7, 61 percent of the survivors had not worked or volunteered in the month before the survey was completed. This compares to 30 percent who stated that they were unemployed prior to the injury.

What is not apparent from the information is how people spend their day. There were no options for day activities other than volunteering, school or paid employment. Meaningful day activity is an area that could be addressed in future planning efforts.

Category	Table 7	
	Current Employment Number	Percent
Total	707	100%
Not working for pay or volunteering	432	61%
Part time paid employment	69	10%
Full time paid employment	48	7%
Volunteer 1-4 hours a month	44	6%
Volunteer 1-10 hours a week	39	6%
Retired	22	3%
Volunteer over 10 hours a week	21	3%
Under 18 years old	7	1%
Unstated	7	1%

#### II.5.2.2. Reason that the person was not currently employed

The surveys offered 10 reasons why the person was not currently employed: inability to find work; inability to perform the previous job; inability to perform any job without help; inability to perform any job; volunteering; in school; enrolled in vocational services; retired due to age; not looking for work for pay; and other. The instructions stated that the person should check all that apply.

Table 8 shows the reasons given on 560 surveys. The remaining 147 surveys were not included in the total because no reason was given or the person was under 18 or retired. The retired category was eliminated from the reasons since it is reported in Table 7. The percentages shown on Table 8 do not sum to 100 percent because the respondents were asked to list all the reasons that applied.

As shown on Table 8, the most common reasons given for survivors not being employed are related to their inability to perform a job. Only 16 percent indicated that it was related to an inability to find a job. It does appear that some of the survivors are retraining themselves by going to school [18%] and/or being enrolled in vocational services [4%].

<b>Table 8</b>			
<b>Reason</b>	<b>Number</b>	<b>Percent of 560</b>	
Inability to perform previous job	206	37%	
Inability to perform any job	178	32%	
Inability to perform any job without help	167	30%	
In school	99	18%	
Other	98	18%	
Not looking for work for pay	93	17%	
Inability to find work	90	16%	
Volunteering	56	10%	
Enrolled in vocational services	25	4%	

### **II.5.3. Post Injury Education**

The questions about post injury education addressed two areas. The first area concerned attendance at grade schools and high schools after the injury. Ninety-four survivors who were injured before 18 or between 18 and 22 years of age attended grade school or high school after the injury. Of these, 54 received special school services. Thirty-eight of the 54 survivors went on to receive a high school diploma or higher. Six more obtained a G.E.D.

The second area concerned attendance at a community college or four year college and use of Disabled Student Services. A total of 367 [52%] survivors attended college after they were injured. Of these, 344 attended community college after they were injured. Ten of the 344 survivors attended a community college and a 4-year college. In addition, 23 survivors attended a 4-year college. The survivors who attended college made heavy use of Disabled Student Services. The surveys indicate that 281 survivors who attended community and four year colleges used Disabled Student Services.

It can be concluded that community colleges are important post injury resources for survivors. There were many comments regarding the value of community college brain injury programs and the recommendation that they be replicated throughout the state.

### **II.5.4. Source of income**

The surveys asked about the survivor's source of income. There were eight options: employment; unemployment compensation; social security, pension, workers' compensation, or other benefits; public assistance; spouse, family or friends; insurance settlement; other settlement; and other. The family and survivor surveys had a different definition for two of the income categories. The family survey included SSI benefits in the definition of public assistance. In the survivor survey, the social security category was not specific about the type of social security and public assistance did not include SSI. To make the comparison clear, the survivor and family survey information is presented separately for public assistance and social security on Table 9.

Table 9 presents the source of income information for 569 survivor surveys and 116 family surveys. There were 22 surveys that did not list any source of income. The instructions on the survey ask respondents to check all of the sources that apply. It is clear from the data that the principal sources of income for survivors came from categories that included social security, and from spouse, family and friends.

Table 9				
Source of Income	Survivors		Family	
	Number	% 569	Number	% 116
Employment	80	14%	19	16%
Unemployment insurance	26	5%	2	2%
Social security, pension, worker's compensation, etc.	406	71%	N/A	N/A
Social security [SSDI or Survivor's benefits], pension, worker's compensation or other earned benefits	N/A	N/A	81	70%
Public assistance excluding SSI	26	5%	N/A	N/A
Public assistance including SSI	N/A	N/A	19	16%
Spouse, family or friends	132	23%	43	37%
Insurance settlement	53	9%	10	9%
Other settlement	23	4%	9	8%
Other	54	10%	7	6%

### II.5.5. Post Injury Impact

The surveys asked how the brain injury had changed the individual's life. Overall, 74 percent of the respondents stated that the injury had made life very difficult or impossible. There were four choices. The 689 responses are summarized under each choice.

- 1) Not at all. No important negative impact of injury. Only 9 [1%] of the surveys indicated that the person had no negative impact as a result of the injury.
- 2) Some. Injury makes a few activities a little more difficult. One-fourth of the respondents indicated that the injury had some impact on the person.
- 3) A lot. Many activities are more difficult. This was the most frequent response with 300 [44%] respondents reporting that the injury had had a significant impact on the survivors' lives.
- 4) Severe impact. Most important life activities are impossible. Thirty percent [207] of the surveys indicated that the survivor's life had been severely impacted by the injury.

## II.5.6. Post Injury Life Changes

The survivor and family surveys asked respondents to rate changes in post injury relationships, employment and living situations, medical health and psychological well-being. There were three choices: better, unchanged and worse.

The results for 698 surveys are shown on Table 10. There were nine surveys that did not answer any of the questions and are not included in the data. The responses that were mixed [e.g., unchanged/better] are shown in a separate column on the table. The overall percentage was calculated by dividing the total responses in each column by the total responses in all columns.

<b>Table 10</b>					
<b>Category</b>	<b>Unchanged</b>	<b>Better</b>	<b>Worse</b>	<b>Mixed</b>	<b>No Answer</b>
Relations with spouse or significant other	17%	13%	41%	1%	28%
Relations with family	28%	24%	41%	5%	3%
Relations with friends	27%	13%	54%	2%	5%
Relations with others	32%	14%	41%	2%	11%
Employment situation	13%	5%	69%	1%	13%
Living situation	32%	19%	40%	1%	8%
Medical health	19%	13%	61%	1%	5%
Psychological well-being	11%	17%	64%	1%	7%
Overall percentage	22%	15%	51%	2%	10%

The most optimistic way to look at the information is to combine the unchanged and better columns. The basis for this is to suggest that post injury life is not worse than pre injury life for the categories that were surveyed.

- Overall, 51 percent of the respondents rated post injury relationships and status as worse. The combined unchanged and better categories were 37 percent. The no answer category was 10 percent of the total.
- The area of greatest negative impact was employment with 69 percent of the surveys reporting that the employment situation had worsened since the injury.
- Post injury relationships with the spouse or significant other were rated as worse on 41 percent of the surveys. The large percentage [28%] of no answers in this category is explained in part by survivors who do not have a spouse or significant other.
- Post injury relationships with the family remained unchanged or improved for 52 percent of the survivors.
- Post injury relationships with friends worsened for 54% of the survivors.

- A greater proportion [46%] of the surveys reported that post injury relationships with others remained unchanged or improved than those that reported relationships with others were worse. [41%].
- Post injury living situations remained unchanged or improved for 51 percent of the survivors.
- Over 60 percent of the surveys reported a negative post injury impact on the medical health and psychological well-being of the survivors.

### **II.5.7. Activities of Daily Living**

The surveys asked the respondents to rate the survivor's ability to perform everyday activities. The activities were grouped into self-care [eating, toileting, bathing and grooming, walking, communication and transferring from a wheelchair] and independent living activities [housekeeping, laundry, shopping and errands, meal preparation and cleanup, telephoning and medication management]. The family surveys included additional activities under self care [dressing] and independent living [transportation, moving around indoors and outdoors, and money management].

The activities were rated using the following definitions.

- 1) Independently/without help for those activities where the person typically completed the activity without help from another person, even if they were slow or used special equipment.
- 2) With help for those activities where someone assisted the survivor. Assistance is defined as physical assistance, reminders, or by staying close in case help were needed.
- 3) Doesn't do for the activities that were never done by the survivor.

Table 11 shows the distribution of the ratings for 700 surveys. The listed activities are those that were on both surveys. As shown on Table 11:

- The survivors were quite independent in self-care activities. The low percentage in the wheelchair transfer activity is attributable to the person not using a wheelchair. In fact, the percentage for that activity may be high. There were surveys where it was obvious that the respondent checked independent in every category even when the survivor did not appear to use a wheelchair.
- A greater proportion of the survivors needed help or didn't do independent living activities than for self-care activities.
  - Telephoning is the exception with 69 percent of the survivors performing the activity independently.
  - Some of the independent living activities are impacted by the living arrangement of the survivor. People who reside in congregate settings are not generally required or expected to engage in housekeeping, laundry, or meal preparation and cleanup. For people living with their families, it was often not clear whether

the survivor did not perform household activities because of ability or the fact that someone else in the household took responsibility for the activity.

<b>Table 11</b>								
	<b>Independently</b>		<b>With Help</b>		<b>Doesn't Do</b>		<b>No Answer</b>	
	<b>#</b>	<b>%</b>	<b>#</b>	<b>%</b>	<b>#</b>	<b>%</b>	<b>#</b>	<b>%</b>
<b>Self-care</b>								
Eating	613	88%	81	12%	1	0%	5	1%
Toileting	599	86%	90	13%	1	0%	10	1%
Bathing/grooming	535	76%	154	22%	1	0%	10	1%
Walking	542	77%	99	14%	44	6%	15	2%
Communication	514	73%	110	20%	22	3%	23	3%
Wheelchair transfer	153	22%	73	10%	374	53%	97	14%
<b>Independent living</b>								
Housekeeping	311	44%	224	32%	145	21%	20	3%
Laundry	333	48%	190	27%	161	23%	16	2%
Shopping/errands	261	37%	278	40%	145	21%	16	2%
Meal prep/cleanup	307	44%	238	34%	140	20%	15	2%
Telephoning	483	69%	121	17%	75	11%	21	3%
Medication management	293	42%	228	33%	156	22%	23	3%

## **II.5.8. Transportation**

The survivor and family surveys included two transportation related questions. The first question asked about the mode of transportation the survivor used to get places [walk, wheelchair, bicycle, drive themselves, ride with family or friends, bus, special disability transportation, and/or other]. A second question asked if the survivor had the transportation he/she needed and if not, what were the needs.

### **II.5.8.1. Mode of transportation**

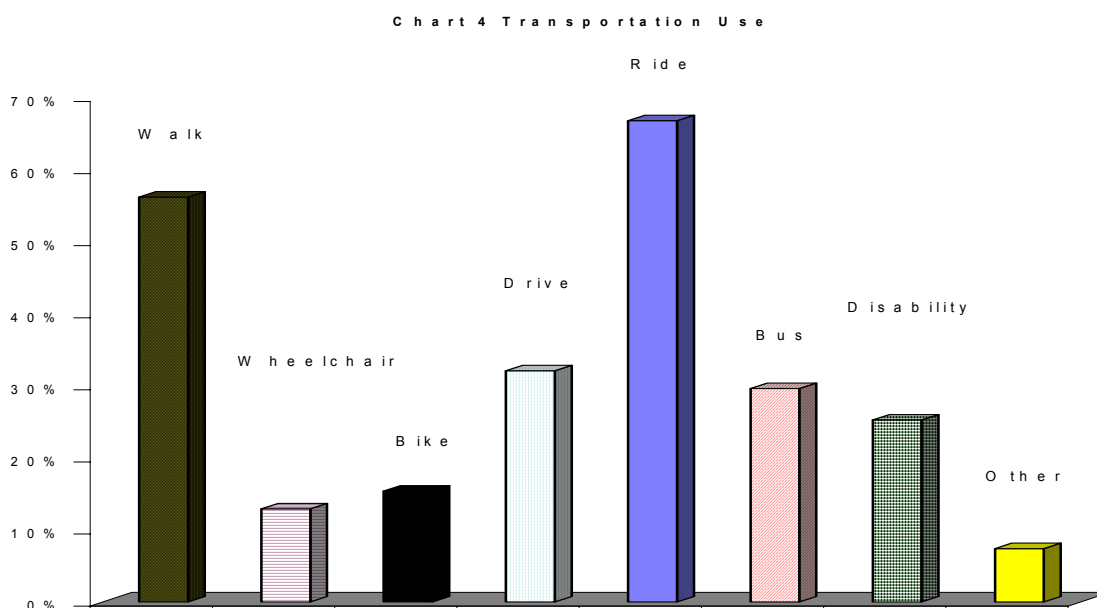
The surveys listed eight modes of transportation: walk, roll by wheelchair, bicycle, drive yourself, ride with family or friends, bus, special disability transportation and other. The respondent was requested to check all that applied. Appendix 3 lists the 83 variations of transportation modes used by 693 survivors. Chart 4 shows the utilization of the eight options. Because of multiple options, the percentages do not sum to 100.

As shown on Chart 4, the two modes of transportation that were reported most often were riding with family or friends [67%] and walking [56%]. The fact that many of the survivors lived with their families may account for the high percentage that rode with



family or friends. The surveys reported less use of publicly funded transportation with 30 percent using buses and 25 percent using special disability transportation.

It is interesting to note that 143 [21%] of the respondents reported that the survivors used only one form of transportation. Of that number, 67 reported that the survivor rode with family or friends, 47 drove himself/herself, 17 used a wheelchair, 15 used special disability transportation, 12 used other transportation, seven walked, and two rode the bus.



#### II.5.8.2. Have needed transportation

The surveys asked whether the survivor had the transportation that he/she needed and if not what was needed. The responses to these questions were surprising. Of the 693 surveys that answered the question, 519 [75%] reported that the survivors had the transportation they needed. The remaining 174 surveys reported that the survivors did not have the transportation they needed. Only 125 of the 174 surveys listed specific transportation needs.

Table 12 lists the needs identified by the 125 respondents as well as comments and needs from 17 surveys that reported the survivor had needed transportation. As shown on Table 12, most of the needs are related to securing personal transportation in the form of a vehicle, driver's license, driver, electric wheelchair, bicycle, ambulance or taxi as opposed to securing public transit.

Table 12		
Transportation Need	Number	Percent 142 surveys
Vehicle [car, van, etc.]	49	35%
Disability transportation/Para transit	18	13%
Transportation to all activities at all times	16	11%
Reliable, timely, flexible transportation	11	8%
Drivers license/training/help getting back	10	7%
Improved/ expanded public transit service	9	6%
Driver	7	5%
Door to door service	6	4%
Access to transportation	5	4%
Assistance in getting/using transportation	5	4%
More people to drive with/alternatives to parents	3	2%
Electric wheelchair	3	2%
Backup transportation	1	1%
Ambulance	1	1%
Better system	1	1%
Bicycle	1	1%
Financial assistance	1	1%
Option to go alone	1	1%
Supervision	1	1%
Taxi	1	1%
Inexpensive transportation	1	1%

## II.6. Impact on the Family

TBI has a dramatic impact on the family of the survivor. The family survey addressed issues that were specific to the family. One set of questions asked families about their concerns for the future of the survivor. Another set of questions dealt with family life after the injury.

### II.6.1. Concerns for the Future

The family survey asked respondents about their concerns for the future of the TBI survivor, including what would happen after the respondent or other family member died. The first question asked whether the respondent was the conservator, guardian or designated payee for the survivor. The second question asked about concerns about the future legal status,

basic living requirements and quality of life issues for the survivor. The third question asked whether legal documents had been prepared.

Table 13 shows the responses to the questions by the respondent's relationship to the survivor. There were seven surveys (a parent, a sibling, a friend and four spouse/partners) that left all of the questions blank. Not all of the respondents answered every question.

About one-third of the respondents were conservators and/or guardians for the survivors. Almost all of the conservators and/or guardians were parents or spouse/partners. Some of the parents were parents of minors. The respondents were the designated payees for 42 percent of the survivors. The high percentage of designated payees may be related to the difficulty that survivors have in managing money.

Respondents expressed great concern about the future legal, basic living and life quality issues for the survivors. The greatest concern was about future life quality issues. The concerns did not translate into preparing legal documents to provide for future financial needs. The numbers under legal documents represent 38 [34%] individual respondents. Nine parents had made arrangements in more than one of the categories.

Table 13								
	Spouse/ Parent	Partner	Sibling	Child	Friend	Other	Total	Percent
Total Respondents	72	24	8	3	2	2	111	100%
<b>Legal Arrangement</b>								
Conservator	21	8	2	2		1	34	31%
Guardian	27	7	1			1	36	32%
Payee	34	11		1			46	41%
<b>Concerns</b>								
Future legal status	45	16	6	1		1	69	62%
Basic living requirements	60	15	7	3	1	1	87	78%
Life quality issues	65	20	8	3	2	1	99	89%
<b>Legal Documents</b>								
Special need trust	14	3					17	15%
Beneficiary	18	4	1				23	21%
Other arrangement	8	6	1			1	16	14%

## II.6.2. Specific concerns about the future

The survey requested respondents to specify their concerns about the future. The 68 responses are powerful statements that express both short-term and long-term concerns. To some extent, the concerns are associated with the kind of relationship the respondent had with the survivor as well as the ages of the survivor and family members

#### **II.6.2.1. Parents [45]**

- Twenty parents expressed concern about what will happen when they are no longer able or around to take care of their family member. Survivors lived with 11 of the parents who expressed the concern. Twelve of the 20 parents are 60-years or older and eight are between 46 and 59 years old. The concerns of the 20 parents ranged from wondering if anyone will be available or equipped to take care of the survivor to concerns about the impact on the families of their other children or the willingness of the other children to take on the responsibility. They are concerned about passing on the responsibility without sufficient financial resources. They are also concerned that their family member may be lonely.
- Thirteen parents expressed concern over current and future financial issues that would impact the ability of their family members to maintain themselves. The issues included the ability to find and keep a job, the cost of finding assistance, the danger of resources running out making it impossible to maintain a decent lifestyle, issues related to maintaining benefits while there is a special needs trust in place, money management problems, and people taking advantage of the survivors.
- Five parents had concerns about finding or maintaining appropriate living arrangements for the survivors. There were concerns about the cost and availability of suitable housing. One parent wanted to bring the family member home but did not have the resources to do so.
- Four parents of minors are concerned about what will happen to their children when they are adults. They are concerned with all areas of life including marriage, employment, ability to make decisions, living arrangements, etc.
- One parent is concerned about the ability of the survivor to continue to survive in the face of his inability to meet his expectations for a normal quality of life.
- One parent is concerned about the lack of TBI resources in the community.

#### **II.6.6.2. Spouse/Partners [12]**

- Four spouse/partners had concerns about what would happen to the survivor when they were no longer able or around to take care of him/her. There did not seem to be people who were available to take over the responsibilities.
- Four spouse/partners were concerned about the quality of life and possibility for fulfillment for the survivors.
- Money management and financial resources was a concern for three spouse/partners.
- One spouse/partner was concerned about the fact that the relationship has changed and diminished as a result of the injury.

### **II.6.6.3. Siblings [8], Children [2] and Friend [1]**

- Seven respondents expressed concerns related to finances. The issues were related to the desire to find a job, fears about what will happen to the current living arrangement when the money runs out, difficulties in holding a job and the reluctance on the part of the survivor to complete paperwork that would make him eligible for benefits. One sibling was worried about the ability of his brother to support and maintain a family on his income.
- Two siblings and the friend are concerned about what will happen to the survivor when the current caretakers die.
- A child stated, “We need help”.

### **II.6.3. Post Injury Family Life**

The family survey asked respondents to respond to 37 statements about the impact of the injury on the family. The statements are grouped into seven categories: financial impact [7], hired assistance [4], future expectations [5], quality of life [7], supports [6], relationships [5], and gathering information [3]. Respondents were asked to indicate whether they agreed, disagreed or were neutral [neither agree nor disagree] about each of the statements. Appendix 4 shows the detailed responses to each of the statements. The results are summarized in the thumbnail sketch of family life that follows.

#### **II.6.3.1. Financial impact**

Most families have had problems with finances as a result of the injury. They have suffered losses of income because they had to take time off from work. Over 60 percent have had to leave a job or reduce work activities in order to carry out their caretaker responsibilities. The loss of income and added expenses has led to a need for additional income for over half of the families who responded to the question. Most of the families have not had to refuse a new job or job transfer because of the injury. One-quarter of the families have had expenses for home modification associated with the injury. Almost 40 percent of the families have had to delay plans for retirement.

#### **II.6.3.2. Hired assistance**

Most families who responded to the questions did not have experience with hiring staff to assist with the care of the family member. Of those that had experience [36], only eight reported that trained staff was easy to find. Only 17 thought staff was dependable. It is clear that the decision not to have staff is related to finances since half of the respondents said they would use staff if someone else paid for it.

#### **II.6.3.3. Future expectations**

Families don't have an optimistic outlook for the future. Forty-four percent do not think that the condition of the survivor will improve. Almost 60 percent think that they will always be responsible for the care of the survivor. Most do not believe that their family member will be able to live independently in the community and worry about who will take over their responsibilities when they are not longer able or die. The families have discussed the future but don't know what to do.

#### **II.6.3.4. Quality of life**

The good news is that family members don't tend to leave because of the stress of the injury. The bad news is that family members haven't returned home to help take care of the survivor. The injury has changed the family's social life. Friends and family visit less often. The respondents are not satisfied with their lives. Almost half report that there are days when they feel they are not able to cope any longer. Over half of the survivors have behaviors that cause problems for the family and others.

#### **II.6.3.5. Supports**

Almost 60 percent of the respondents felt that their family could benefit from counseling to help cope with the life changes brought on by the injury. Over half would like to meet with other families for support. Seventy percent of the respondents did not feel that there were adequate services in their community for TBI. Forty-seven percent of the respondents did not feel that their private insurance/HMO was helpful in meeting the needs of the survivors.

Surprisingly, only 40 percent of the respondents wanted respite or relief. About the same percentage found it difficult to get help from other family members. Forty-seven of the respondents stated that they would like respite while 36 disagreed and 31 were neutral. The responses were not tied to the living arrangement of the survivor. Twelve of the 47 families who wanted respite or relief had a family member who lived outside of the family home. Twenty-two of the respondents who did not want respite had family members who lived with them. Eight of the 31 respondents who were neutral had family members who lived with them.

#### **II.6.3.6. Relationships**

Respondents said relationships with spouses and significant others are more difficult since the injury. The reaction to statements about other relationships was mixed. About one-third of the respondents felt they did not have enough time to spend with their non-disabled child/children. About one-third has avoided pursuing new relationships since the injury. Forty-one percent stated that relationships in the family are stronger since the injury, but 52 percent said that relationships with other family members have become more stressed.

#### **II.6.3.7. Gathering information**

Over half of the respondents reported that information about brain injury and services had not be readily available and that they did not have enough knowledge regarding brain injury. Sixty percent reported that they did not understand federal and state financial benefits and programs.

### **II.7 Summary**

The survivor and family surveys have provided a great deal of useful information that will be incorporated into the needs assessment that is in the next section of this report. One of the most interesting things about the surveys is the clear picture they provide about survivors and families.

What we have learned is the average survivor described in the surveys is a single White male about 43 years old who lives in a private residence and is supported by public funds and help from family and friends. He is better educated than the general population having achieved at least a high school diploma and has attended community college since the injury. He is not employed because of the effects of the injury. He walks or uses private transportation to get around. He relies on rides from family and friends. His injury was caused by a traffic accident when he was 30. He was unconscious for a considerable amount of time after the accident.

Families have absorbed the financial and caretaker impact of the injury. They are stressed and are fearful of the future of their family member who has been injured. They have had to learn about services and resources on their own and do not feel well informed about what is available.

## **III. Needs**

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### **III.1. Information Sources**

A needs assessment is a required component for the TBI Planning Grant. Information on needs was collected through surveys of survivors, family members, providers, state agencies, county mental health departments and county health officers. Additional information was gathered through public forums and focus groups held throughout the state. Information from the Advisory Board focus group was also considered. [Appendix 5] Each of the information sources has strengths and weaknesses, which should be taken into account when evaluating needs.

#### **III.1.1. Survivor and Family Surveys**

The survivor and family surveys included five sources of information on needs: adequacy of transportation; a listing of service needs [Appendix 6]; general questions regarding receipt of and satisfaction with services [Appendix 6]; and open ended comments [Appendix 7]. The family survey asked for additional information in two areas: ratings of services received from various agencies and organizations [Appendix 8] and a list of 31 needs as compared to 25 needs on the survivor survey [Appendix 6].

There are three areas of concern.

- 1) The method of distribution does not guarantee that the respondents are representative of the population impacted by TBI.
- 2) The surveys include a question regarding the kinds of services the survivor receives or needs. There is no indication of who provides or funds the services or the quality of the services.
- 3) The surveys provide a “point in time” picture of the service delivery system.

The strength of the survivor and family surveys lies in the wealth of information shared in the comments and the consistency of the responses that describe the service delivery system, delineate areas of need and speak to the impact of the injury on the individual and the family.

#### **III.1.2. Provider Surveys**

The provider survey asked questions regarding the services provided, identification of service needs gaps in the system [Appendix 9], ratings for the format for training and informational materials, ratings for service delivery within their geographic area, referral sources, interagency agreements, and interest in participating in future planning activities.

There are three areas of concern.

- 1) The method of distribution for provider surveys does not guarantee that all of the resources in the state were included. Therefore, the responses may not fully describe the resources in the state.



- 2) The survey asks about the services provided by the agency. The listing of services does not include definitions leaving it open to interpretation of the respondent. This makes it difficult to compare the scope of services across providers. There is also no way to judge the quality of the services provided.
- 3) Some of the questions ask for ratings of services and gaps in the service delivery system. It is not clear whether the responses to the questions represent the agency or the respondent.

The strength of the survey lies in the identification of resources in various geographic areas in the state. The resources provide a starting place to build a more comprehensive catalog of services. Other strengths include identification of gaps in services in the geographic area and statements of interest by respondents in participating in planning and other activities.

### **III.1.3. State and county agencies**

State and county agencies were asked about eligibility for services, services provided by the organization, inter-organization participation among agencies that serve individuals with TBI, and gaps in services related to TBI.

The survey of state agencies does not represent the way that California does business as compared to other states. Very few California state agencies provide direct services. Most state agencies either contract for or fund service delivery through local agencies, organizations or groups. So the fact that the particular state agency or department does not directly serve the population does not mean that they don't fund the delivery of the service.

The strength of the state survey is that it provides some indication of the services provided by the agency and includes a contact person for future inquiries.

The survey of county agencies points up the fact that TBI is not a recognized eligibility criterion for services in the local agencies. The strength lies in the statements about the services provided and a contact person for future inquiries.

### **III.1.4. Forums and Focus Groups**

Participants in the forums provided information on the status of the service delivery system from the perspective of those who use or participate in the system directly. The information provides an insight into how the strengths and weaknesses of the service delivery system impact the lives of survivors.

The strength of the forums and focus groups is that they provide a statewide perspective and cover a two-year period. The forums and focus groups were well attended. The fact that the information from participants throughout the state on service gaps and needs is consistent with the surveys adds weight to the assessment of needs. An additional strength is the fact that the forums and focus groups were spread across two years, which reduces the likelihood that the information was unduly affected by current events.

The weakness is that there was no way to determine how representative the participants were of the rest of the TBI population.

## **III.2. Needs**

The needs are presented in two broad categories: 1] system building and 2] post injury community integration needs. System building needs tend to be overarching needs for the total system and can be thought of as foundational since they are essential components of an effective and integrated service delivery system. Post injury community integration services are those services and supports that assist survivors and their families to achieve an acceptable quality of life after the acute stage of the injury.

### **III.2.1. System Building Needs**

Empowerment is the outcome of effective system building. When an effective system is in place survivors and families have the tools and resources to obtain necessary services and supports. System building needs are interdependent. It is often difficult to separate them into discrete needs. For example, public awareness depends upon information and advocacy to achieve the desired outcome. Access to services and supports depends upon public awareness, information, advocacy and interagency collaboration.

One way to think about system building needs is to envision an ideal system and then construct the components that will achieve the system. The Advisory Board engaged in a focus group exercise to describe the current system, to identify what was working in the current system and to identify the essential components of an effective service delivery system. When that focus group information is laid against what others say in the surveys, forums and focus groups, a very clear picture emerges for system building needs. The Advisory Board focus group summary is found in Appendix 5.

The surveys, focus groups and forums identified public awareness, information, advocacy, eligibility, access to services and supports, improved infrastructure, case management, support groups, and funding, as needs that fall within this category. In some cases the need is easily quantifiable. In other cases the need arises out of an overall impression of the system need that would best address concerns expressed by survivors and family members. There is no particular significance to the order in which the needs are discussed.

#### **III.2.1.1. Public/professional awareness and education/training**

The need to increase public awareness about TBI and its effects was a recurring theme in the comments made by survivors, families and providers. Public awareness is an expansive term. The term includes education of the general public, medical and other professionals, employers, schools, law enforcement, the court system, providers and governmental agencies. There is a perception among survivors, families and providers that TBI is invisible. They say that the public views survivors as “looking okay” and since they “look okay” there is not appreciation or acceptance of the impact the TBI has had on the individual and his/her ability to reintegrate into society. The lack of understanding of TBI and its impact on the future of the survivor extends to the professions that are best equipped to assist survivors in successful reintegration into the community.

There was not a specific question on the surveys about public awareness. There were 389 survivor and family surveys that included comments. [Appendix 6] Thirteen percent cited public awareness and education/training as a need. There were 155 provider surveys that identified specific needs and gaps in the system. [Appendix 9] Sixteen

percent cited public awareness and education/training as a need. In addition, public awareness and education/training was the most common concern expressed in the public forums and was one of four major themes at the focus groups.

### **III.2.1.2. Information**

The need for information was also a recurring theme. Survivors and family members cited the lack of information on TBI, resources, services, eligibility criteria, benefits, support groups, etc. as the most frustrating barrier in the system. Essentially, what they want to know is what to expect, what is available and how do they get it. Everyone felt that they had to find the answers on their own. There is consensus that information should be readily available and accessible to survivors, families and providers. The information on resources and services should be given to the survivor and family member as soon as possible and should be routinely given as part of the discharge planning from the hospital. There is also consensus that there should be a single, easily accessed source for the information such as a central website that would have all the available information. Information should be presented in a way that is easily understood and in languages other than English.

The family survey included a section with statements about information. [Appendix 4] Respondents were asked to state whether they agreed, disagreed or were neutral. Fifty-two percent of the respondents disagreed with the statement that information had been readily available. Fifty-one percent did not feel that they had enough knowledge regarding brain injury. Sixty-one percent did not understand available federal and state financial benefits and programs.

Another section of the family survey asked the families to rate various services as to whether they were easily available, capable and skilled, consistent and dependable, and provided in a timely manner. [Appendix 8] The respondents were given five options: strongly agree, agree, neutral, disagree, strongly disagree, and don't know. The respondents were instructed to mark "Don't know" if they had no experience with the service. There were 122 respondents who rated one or more of the services. Overall, 52 percent of the responses were "Don't know". The California Brain Injury Association, Center for Independent Living, Caregiver Resource Center, employment services, IHSS, private pay attendant services, housing services, nursing home services and respite care services had the highest percentages of "Don't know". Medicare/Medi-Cal, medical rehabilitation services, and social security services had 20 to 30 percent response of "Don't know". Comments made on the surveys suggest that the high rate of "Don't know" responses is at least in part related to the lack of information about the services.

There were no specific questions on the survivor survey about information. Eleven percent of the 389 survivor and family surveys with comments cited information as a need. Some of the longest narratives related to the frustrations around the lack of information.

Information was cited as a specific need in the public forums. The focus groups cited information as a specific need and a factor in relation to access barriers.

Providers were asked whether they knew about the Brain Injury Association of California or the California State funded Traumatic Brain Injury Project administered by DMH.

Eighty-three percent of the respondents who provided TBI services knew about the Brain Injury Association and 55 percent knew about the TBI project.

Sixteen percent of the 155 provider surveys that included comments on needs and service gaps identified the need for information. Providers were also asked to indicate the sources of information that would help develop staff knowledge and skills related to TBI. The choices were: in-service, written resources and materials, regional workshops, national workshops, mobile multi-disciplinary resource teams, videotapes, the Internet, or other. The ratings were: 1=least important, 2=needed and 3=most needed. One hundred seventy-four surveys included ratings. The average for each source of information is shown on Table 14.

Table 14	
Source of Information	Average Rating
Written resources and material	2.4
In-service	2.2
Regional workshop	2.2
Videotapes	2.1
Mobile multi-disciplinary resource teams	1.8
Internet	1.7
National workshop	1.4

### III.2.1.3 Advocacy

Advocacy is a term that covers advocacy for the system and advocacy for individual users in the system. System advocacy includes active promotion of TBI needs and issues within state government and agencies, local governments and agencies, service delivery agencies and organizations, public and private funding sources, the educational system, professionals, and the community at large. Systems advocacy is proactive and requires dedication and energy.

Individual advocacy is related to obtaining needed services, supports and funding for individuals. Individual advocacy can be incorporated into the system building activities by identifying resources for the service as well as providing training and information to individuals on their rights. Individual advocacy is most effective when the system advocacy has laid the foundation.

Based upon the comments in the surveys, forums and focus groups, it appears that system advocacy and resources for individual advocacy are lacking. It is difficult to quantify the need for advocacy. The most direct statements expressed the need as making ADA work for TBI survivors, fair treatment at service agencies, recognition and treatment with dignity. Other statements were less direct and were targeted at funding for the system, access to generic services, knowledge of TBI, etc. Advocacy is a necessary component in obtaining many of the needs.

Sixteen percent of the survivor and family surveys with comments had specific advocacy issues. Advocacy was one of the four major themes of the public forums. However,

these numbers understate the underlying issue of advocacy in the other comments made on the surveys, in the forums and in the focus groups.

#### **III.2.1.4. Point of entry into the service delivery system**

Planning and system development rely on knowledge about the size and characteristics of the population to be served. The current system is fragmented. There is no defined point of entry into the service delivery system. Generally the first point of contact with the system is through a hospital. There is no systematic identification and tracking system in place to identify survivors after the initial surveillance activities. No one knows with certainty the number of survivors, their demographics, where they live, how their needs change over time or their current service and support needs.

The comments on the surveys suggest a need for a defined point of entry into the system. The point of entry would include active case finding and the provision of comprehensive information and referral to resources. Fifty-nine percent of 120 families identified that the survivor needed help in connecting with resources. [Appendix 6] Ten percent of the 155 provider surveys with comments recommended a single point of entry, case finding and tracking, and referrals. [Appendix 9]

#### **III.2.1.5. Case management/service coordination**

Case management/service coordination is the link between survivors and families and resources. Some examples of case management/service coordination activities are identifying needs, developing service plans, coordination of services and supports, accessing services and supports in the community, understanding eligibility criteria for generic services, advocacy, and ongoing monitoring of the effectiveness of services and supports. Comments on the surveys suggest that effective case management/service coordination could make a huge difference in community reintegration and achieving an acceptable quality of life for survivors. A recurring theme was the difficulty that survivors and families have in coordinating services from independent organizations in the community. Service coordination poses a significant challenge to persons who have varying problems with memory, organization, planning, and/or problem solving as well as financial and/or physical constraints.

As shown on Appendix 6, 34 percent of the 680 surveys indicated a need for service coordination. In addition, 10 percent of the survivor and family comments and 19 percent of the provider comments cited case management as a need. There were several people who spoke about the need for case management at the January 2002 forum in San Diego. The Chairperson of the San Diego Brain Injury Collaboration cited case management as one of four most critically needed services in the community. The San Diego Brain Injury Foundation listed long term case management services as a need.

#### **III.2.1.6. Eligibility and access to services**

Eligibility and access to publicly funded resources and services is a major issue for survivors. The two access issues are eligibility criteria and the lack of publicly funded services designed to meet the special needs of survivors. The second issue is discussed below.

Having a traumatic brain injury is not enough to qualify for most publicly funded services. The survivor must also meet the categorical eligibility requirements for services provided through mental health and health departments, regional centers, Social Security, IHSS, Medicare and Medi-Cal.

Families and survivors expressed frustration about TBI not being a recognized qualifying condition for publicly funded services. As shown on Appendix 8, 46 percent of the 120 family survey respondents disagreed or strongly disagreed that Social Security services were easily available and 31 percent disagreed or strongly disagreed that Medicare or Medi-Cal was easily accessed. Difficulty in accessing and maintaining publicly funded services was reported on 11 percent of 389 survivor and family surveys. Eligibility requirements were identified as one of the barriers to access to services in the focus groups. There were also comments regarding the eligibility barrier in the public forums.

#### **III.2.1.7. Access to appropriate services**

Another access issue discussed in the survey comments, forums and focus groups is related to the appropriateness of the publicly funded services and supports. The concern is that the services provided by state funded programs are not designed to meet the needs of TBI survivors. The most often cited example is Department of Rehabilitation [DR] services. DR services are short term in nature and do not take into consideration the realities of having memory problems, or a need for ongoing job coaching and job accommodations.

#### **III.2.1.8. Improved infrastructure**

Fragmentation, inconsistency and limited services and supports have been identified as weaknesses in the current system. There appears to be consensus that the infrastructure of the service delivery system needs to be improved and strengthened. The improvements include creation of a seamless continuum of care that begins with the injury and extends through reintegration and support in the community. The ideal system would include networking between public and private providers of services, collaborative planning and program development, improved communication, long term support for survivors and families, consistent information and protocols, more uniform availability of services in all areas of the state, and replicating or expanding models that are successful.

The best source for ideas about improving the infrastructure is found in the provider surveys. There were 155 surveys with a total of 653 comments [Appendix 9] on needs and gaps in services. The comments have been grouped into related categories. Almost all of the comments, regardless of the category, relate to improving the infrastructure. Improving the infrastructure was also a major theme in the public forums and focus groups.

#### **III.2.1.9. Funding the system**

The TBI service delivery system in California is not well funded. The comments and suggestions in the surveys, focus groups and forums tend to be about services that need to be funded rather than sources of funds. However, it is clear that there is an expectation that a stable and long-term source of funding be identified.

The funding suggestions in the forums include Medicaid Waivers, a combination of public and private funding, to be active in the legislative process to obtain increased funding, funds from drunk driving infractions, and grant and foundation money.

#### **III.2.1.10. Funding for services and supports**

Funding for services and supports for individuals comes from private insurance, HMOs, Medicare, Medi-Cal, state disability payments, Social Security, IHSS, individual and family resources, and state agencies [e.g. Department of Rehabilitation]. There is concern about the access to and restrictions on services and supports that are placed upon individuals who are indigent, low-income workers, or who rely upon Medicare and Medi-Cal. There is also concern about the lack of funding for individuals after they exhaust their benefits with insurance and HMOs. There is a perception that affordable services are lacking in the system and a fear that eventually everyone will run out of money to pay for the needed services. Families were particularly worried about the future of their family member when parents were no longer able or around to assist in the payment or provision of services.

#### **III.2.1.11. Long-term support**

There were numerous references and some specific comments about the need for ongoing long-term support for survivors. There seems to be consensus that the effects of TBI are long-term and that while specific needs may change, the need for support continues. Many of the comments were made in reference to other service needs, but it was clear that respondents and participants felt that long-term support is an important component of any future service delivery system.

#### **III.2.1.12. Support groups for survivors, caregivers, family members and others**

Survivors, family members, caregivers and providers value support groups. Support groups were described as providing information, encouragement, assistance with self esteem, a form of respite and relief for caregivers, companionship, understanding, and growth opportunities for survivors, family members, caregivers and others. Support groups were viewed as resources for newly injured. People want more accessible, frequent, local, specialized, and multi-cultural support groups. There was a suggestion that there be a website that lists all of the support groups along with the leader so that people could contact them.

As shown on Appendix 4, 56 percent of the families felt that it would be helpful to meet with other families. Twelve percent of the provider surveys with comments and 8 percent of the survivor and family surveys with comments recommended support groups. More support groups were also recommended at the public forums and in the focus groups.

### **III.2.2. Post Injury Community Reintegration Needs**

Post injury community reintegration needs are services and supports for the individual and family. Survivors, families and providers identified a rich array of service and support needs. Since planning is the purpose of the needs assessment, the report emphasizes the services and supports that were cited most often as needs. Limiting the discussion to the most

needed services and supports is not meant to diminish the importance of other services to the lives of survivors. Appendices 6, 7, and 9 list all of the needs identified in the surveys.

Living options, meaningful day activities, transportation, social/recreational opportunities, and various services to mitigate the long-term impact of the injury were among the most needed services. The determination of need is based several factors.

- 1) A high percentage of reported need on the survivor, family and provider surveys, including comments.
- 2) The themes of the public forums and focus groups.
- 3) Factors such as the age of parents that were revealed in the analysis of data.
- 4) Services for populations not included in the survey data such as children.

#### **III.2.2.1. Employment and meaningful day activities**

Employment and meaningful day activities include paid employment, vocational training, supported work, job training and placement, volunteer opportunities, day programs, adult day health programs, clubhouses, etc. A significant number of survivors reported that they were neither looking for paid employment, engaged in volunteering nor in school. [There were no questions regarding how the survivors spend their day.] The surveys included complaints about the Department of Rehabilitation, the high cost of day activity programs and comments about the difficulty survivors have in maintaining paid employment.

The need for employment and job training received the highest percentages among the list of service needs on the survivor and family surveys. Forty-six percent indicated a need to find paid employment; 47 percent indicated a need for training in the community to increase job skills; and 43 percent indicated a need for increasing educational qualifications. Sixteen percent of the comments on survivor and family surveys were related to employment and day activities. Almost half of the 155 provider surveys indicated that vocational, employment and day activities were a need. The need for productive day activities was discussed at the public forums.

#### **III.2.2.2. Living options**

Living options is a broad category that includes the whole continuum of living arrangements. The options range from living independently in the community to living in a long-term care facility. The options included transitional housing. People generally described desirable arrangements as affordable and with an appropriate level of support.

The real need for living options outside of the family home may exceed the 33 percent of survivors and families who indicated a need for assistance in "Finding housing that is affordable and accessible". [Appendix 6] Only 26 percent said the survivor was receiving the service. The people who did not answer the question tend to be satisfied with their current living arrangement. But the large number of survivors who live with aging parents suggests that there will be an increasing need for living options outside of the family home.



Twenty percent of the 389 family and survivor surveys with comments stated that housing was a need. Fifty-five percent of the 155 provider surveys that listed needs and service gaps listed housing as a need. Housing needs were discussed at the public forums and focus groups.

### **III.2.2.3 Transportation**

Transportation is an obvious need that impacts any population that relies on publicly funded transportation. Transportation can also be a problem for people who must rely on others to transport them. Problems with publicly funded transportation were cited in the public forums, focus groups and comments on surveys. The problems included difficulty in arranging and using paratransit, finding transportation that crossed local municipal and county boundaries, transportation schedules, lack of flexibility, cost and availability of transportation in rural areas. There were also problems associated with the ability of the survivor to use public transportation without assistance. Survivors and family members expressed interest in having transportation alternatives that did not rely on family and friends.

As discussed in an earlier section of this report, the survivor and family surveys did not express an overwhelming need for transportation. Seventy-five percent of the surveys indicated that the survivor had transportation. Most of the 125 surveys with comments about needed transportation wanted some form of private transportation such as a vehicle or drivers license. However, many survivors who reported that they had transportation relied on family and friends.

Transportation was identified as a major need in the forums and focus groups. Eighteen percent of the 155 provider surveys indicated that transportation is a need.

### **III.2.2.4. Services related to injury**

The survivor and family surveys included three categories of service needs related to the lasting effects of the injury.

- 1)** The first category is for cognitive and emotional issues such as improving memory and solving problems; improving mood; controlling temper; managing stress and emotional upsets; expressing needs; and understanding others.
- 2)** The second category relates to everyday activities such as eating, bathing and dressing; money management; handling legal problems; housekeeping, cooking, etc.; personal care attendant; and child care.
- 3)** The third category relates to physical and health issues such as increasing independence in walking, balancing, and lifting, and improving his/her health.

Table 15 shows needs listed on 20 percent or more of the surveys. As shown in the table, the respondents to the surveys rated cognitive and emotional issues as the greatest unmet needs for survivors.

Table 15		
Need	Number	Percent
<b>Cognitive and emotional needs</b>		
Improving memory/solving problems better	324	48%
Managing stress/emotional upsets	287	42%
Expressing needs/understanding others	262	39%
Improving mood	267	39%
Controlling temper	221	33%
<b>Everyday Activities</b>		
Independence in housekeeping, cooking	211	31%
Handling legal problems	206	30%
Personal care attendant	160	24%
<b>Health issues</b>		
Improving health	211	31%
Walking, lifting, balancing	211	31%

### III.2.2.5. Social and recreational opportunities

A common theme among the comments on survivor and family surveys that is reflected in the listing of services is the need for social and recreational opportunities for survivors. Loss of friends is a reported impact of the injuries. Survivors are anxious to have friends, relationships and activities in the community. They are inhibited by the lack of information, opportunities, transportation and finances. It was a hopeful sign that a representative from a local parks and recreation department attended one of the forums and asked how jurisdiction could help.

Forty-seven percent of the survivor and family surveys indicated a need for places and opportunities to socialize, 36 percent indicated a need for opportunities to participate in sports and recreation programs. Twelve percent of the surveys with comments asked for social and recreational opportunities.

### III.2.2.6. Family support

The survey data indicates that families directly provide or fund services for many survivors. The families do not receive a lot of assistance. This is an area for further exploration as to needs.

#### **III.2.2.7. Service needs of populations not included in source data**

Service needs for children, survivors 60 years and older, and multi cultural populations are not included in this report because of lack of information on service needs. This is an area for further exploration.

### **III.3 Summary of Needs**

There was a great deal of consistency among survivors, families and providers about system, service and support needs. The consistency ran through the surveys, forums and focus groups. The identified needs validate the description of the current service delivery system as being fragmented and in need of attention.

## **IV. Resources**

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The final requirement of the third Core Capacity Component of the Planning Grant is an assessment of resources of the full spectrum of care and services from initial acute treatment through community reintegration for individuals of all ages having TBI.

### **IV.1. TBI Resources Established by Department of Mental Health [DMH]**

DMH has taken a leadership role in establishing and funding two community-based programs for persons with TBI. The programs are the Caregivers Resource Centers and the TBI project sites.

#### **IV.1.1. Caregiver Resource Centers**

There are 11 non-profit Caregiver Resource Centers that provide services to support families and caregivers who care for adults with chronic brain disorders including TBI. The services are designed to deter institutionalization, allow caregivers to maintain a normal routine and quality care. The Caregiver Resource Centers served 12,348 clients in fiscal year 2000.

The range of services include:

- Specialized information and referrals
- Family consultation/care planning
- In-home assessment of caregiver needs
- Vouchered legal and financial planning with attorneys
- Psycho educational classes
- Short-term counseling [individual, group, family]
- Respite care
- Support groups
- Caregiver education and training

A separate state contract funds a Statewide Resource Consultant to operate a statewide clearinghouse on caregiving and brain disorders; conduct education; training and applied research; carry out policy development; maintain a statewide database on CRC clients served and provide technical assistance.

Table 17 shows the location and service delivery area for each Caregiver Resource Center. The Statewide Resource Consultant is located in San Francisco.

<b>Table 17</b>		
<b>Caregiver Resource Center [CRC]</b>	<b>Location</b>	<b>Service Delivery Area</b>
Bay Area CRC	San Francisco	Alameda, Contra Costa, Marin, San Francisco, Santa Clara, and San Mateo Counties
Coast CRC	Santa Barbara	San Luis Obispo, Santa Barbara and Ventura Counties
Del Mar CRC	Salinas	Monterey, San Benito and Santa Cruz Counties
Del Oro CRC	Carmichael	Alpine, Amador, Calaveras, Colusa, El Dorado, Nevada, Placer, Sacramento, San Joaquin, Sierra, Sutter, Yolo and Yuba Counties
Inland CRC	San Bernardino	Inyo, Mono, Riverside and San Bernardino Counties
Los Angeles CRC	Los Angeles	Los Angeles County
Mountain CRC	Chico	Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama, and Trinity Counties
Orange CRC	Fullerton	Orange County
Redwood CRC	Santa Rosa	Del Norte, Humboldt, Lake, Mendocino, Napa, Solano and Sonoma Counties
Southern CRC	San Diego	Imperial and San Diego Counties
Valley CRC	Fresno	Fresno, Kern, Kings, Madera, mariposa, Merced, Stanislaus, Tulare and Tuolumne Counties

#### **IV.1.2. TBI Project Sites**

In 1991 DMH awarded demonstration grants to four organizations to provide post-acute services to individuals with traumatic brain injury. The purpose of the grants was to determine the effectiveness of providing coordination of care and services to adults with TBI after the person had completed medical rehabilitation. Two additional sites were added in 1999. Three of the sites are in Northern California and three are in Southern California.

The project sites provide or coordinate five services.

- Information, referral and coordination services that include providing information about local resources and assistance in identifying, accessing, utilizing and coordinating services for TBI survivors and their families.
- Community reintegration services to increase or maximize the survivor's ability to live and participate in the community.
- Supported living services to provide support and training in the survivor's residence to improve independence.

- Vocational supportive services that may include prevocational or educational services to help the survivor to succeed in the workplace.
- Public and professional education to improve the survivors' access to services and the system of services.

Table 18 shows the location and service delivery area for each site.

<b>Table 18</b>		
<b>TBI Project Site</b>	<b>Location</b>	<b>Service Delivery Area</b>
Coordinated Care Project	Mercy General Hospital Roseville CA	Sacramento, Placer and El Dorado Counties
San Francisco TBI Network	RCH, Inc. San Francisco, CA	San Francisco County
New Options TBI Project	Central Coast Center for Independent Living Capitola, CA	Santa Cruz County
Brain Injury Network	St. Jude Medical Center Fullerton, CA	Orange County
Project Connections	The Betty Clooney Foundation Long Beach, CA	Los Angeles County
TBI Resource Network	Casa Colina Career Development Center Pomona, CA	San Bernardino County

## **IV.2. Other Publicly Funded Community-Based Resources**

There are a number of publicly funded community-based resources that provide services to individuals with TBI. This section describes resources that provide direct services to individuals with TBI.

### **IV.2.1. Centers for Independent Living**

There are 29 centers for independent living with 66 sites in California. The centers serve people with disabilities, including TBI survivors. The centers receive federal and state funding. Centers must meet the requirements of Title VII of the federal Rehabilitation Act and California law, which include the provision of specific core services. The federal requirements include the provision of peer support, advocacy, information and referral, and independent living skills training. California added two additional services, accessible housing referral and personal assistance referral.

### **IV.2.2. Regional Centers**

There are 21 regional centers in California. The regional centers are non-profit community-based organizations funded by contract with the Department of Developmental Services to provide case management and purchase of services for persons with developmental disabilities. The regional centers were created by and operate under the requirements set forth in the Lanterman Act [Welfare and Institutions Code 4500 et. seq.]

The Lanterman Act defines a developmental disability as, *“a disability which originates before an individual attains age 18, continues, or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual. As defined by the Director of Developmental Services, in consultation with the Superintendent of Public Instruction, this term shall include mental retardation, cerebral palsy, epilepsy, and autism. This term shall also include disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation, but shall not include other handicapping conditions that are solely physical in nature.”*

Regional centers serve individuals with TBI who meet the eligibility requirements. The regional centers provide or fund a full array of services and supports to meet the needs of an individual throughout his/her life. The services and supports are delineated in an individual program plan or an individual family services plan depending upon the age of the person.

#### **IV.2.3. Community Colleges and Four Year Colleges**

Community colleges are an important community-based service for individuals with TBI. There are 108 community colleges in California. The services provided by the colleges include accommodations and supports for disabled students including individuals with TBI. A number of the colleges provide specialized acquired brain injury [ABI] programs to assist survivors to obtain the community reintegration skills.

Four-year colleges also provide special assistance to disabled individuals including TBI.

#### **IV.2.4. Department of Rehabilitation [DR] Vocational Rehabilitation Services**

DR provides vocational rehabilitation services to persons with disabilities, including TBI. The services are provided throughout the state in 100 field offices in 17 districts. DR describes the purpose of its vocational rehabilitation services program is to assist *“Californians with disabilities obtain and retain employment and maximize their ability to live independently in their communities. The Department develops, purchases, provides, and advocates for programs and services in vocational rehabilitation, habilitation and independent living with a priority on service for persons with the most severe disabilities.”*

The following list of some of the services DR provides is from the DR website.

- Counseling and guidance
- Referrals and assistance to get services from other agencies
- Job search and placement assistance
- Vocational and other training services
- Diagnosis and treatment of physical and mental impairments
- Maintenance for additional costs while participating in the IPE
- Transportation, if needed
- On-the-job or personal assistance services

- Interpreter services
- Rehabilitation and orientation/mobility services for individuals who are blind
- Occupational licenses, tools, equipment, initial stocks and supplies
- Technical assistance for self-employment
- Rehabilitation assistive technology
- Supported employment services
- Services to the family

### **IV.3. Medical rehabilitation**

California has a network of excellent medical rehabilitation facilities that provide post acute TBI services. The facilities include Rancho Los Amigos in Downey that operates a nationally recognized Adult Brain Injury Program; Casa Colina Rehabilitation Systems that provides a spectrum of TBI services from acute rehabilitation through community support; and the University of California San Francisco affiliated San Francisco Injury Center where pioneering work on the effects of hypotension and hypoxia following TBI has been done.

The Santa Clara Valley Medical Center houses the Northern California Traumatic Brain Injury Model System of Care program funded through the National Institute on Disability and Rehabilitation Research as a Model System for TBI. The program, one of 16 centers across the United States, has been designated as a Model System since the inception of the program. The continuum of care includes those with mild TBI, very severe brain injuries and those transitioning into the community.

### **IV.4. Resources Identified Through Surveys**

Information for the assessment of resources was gathered through two survey instruments. A 10-page survey was sent to state agencies, county mental health departments, and county health officers. An eight-page survey was sent to providers. The strengths and weaknesses of the information sources are discussed in Section III of this report.

#### **IV.4.1. Survey of State Agencies**

Sixty-one 10-page surveys were sent to state agencies. In some cases more than one survey was sent to a state agency. It has been noted that California state agencies do not generally provide direct services. [Department of Rehabilitation is the exception.] The response to the survey reflects that fact. Forty-eight surveys were returned. Of these, 37 stated that they did not provide services to individuals with TBI. Most of the 37 surveys stated that the agency did not provide direct services.

Two of the 11 surveys that indicated that individuals with TBI were eligible for services were identical. None of the agencies had special programs for TBI. People were eligible for the services provided if they met the eligibility requirements of the program. None of the surveys included information on gaps or service needs.



#### **IV.4.2. Survey of County Mental Health Departments**

In California, counties are responsible for community-based mental health services. The counties have organized in various ways to carry out the responsibility. Fifty-nine surveys were mailed to organizations on the County Mental Health Departments mailing list. The list includes 57 county departments [Sutter and Yuba counties share a mental health department], the Berkeley City Mental Health Department, and Tri-City Mental Health Center in Pomona.

The 10-page survey began by asking whether individuals with TBI were eligible for services. If the answer to the question was “no”, the survey was concluded. Thirty-five responses were received from 34 departments. In general, the responses indicated that a diagnosis of mental health or, in some cases, substance abuse was required to receive services.

Alameda County was an exception. Alameda County and other Bay Area mental health departments have a program that serves “low-income neurobehavioral clients who are not placeable in other settings.” The program “operates at three sites and provides on-going inpatient neuropsychological/behavioral and medical management of complex clients with acquired brain injuries, whether from trauma or neurological disease.” The clients are served in locked or secured settings with trained staff. The facilities provide “skilled nursing level care plus neurobehavioral programming for a daily supplement to the Medi-Cal rate.” The Bay Area county mental health departments absorb the cost of the program.

Eleven surveys included information on gaps in services for individuals with TBI. The 11 surveys cited a need for an agency with a mandate to serve TBI as well as funding for a full array of services including day activities, case management, and living options.

#### **IV.4.3. Survey of County Health Officers**

The 10-page survey was sent to 63 designated health officers on the County Health Officers mailing list. The list includes four cities that are responsible for delivery of health services, Berkeley, Vernon, Long Beach and Pasadena. Los Angeles County received two surveys. The survey format is identical to that used to survey county mental health departments.

Eighteen completed surveys were returned. Three of the 18 surveys were from Yolo County. Eight of the 18 surveys, including three from Yolo County, indicated that they provided services to persons with TBI.

Five of the eight surveys were for the county administered California Children’s Services [CCS] program. The CCS services were provided to children under the age of 21-years who met the medical and income qualifications associated with the program. Non-medical support services [vocational, educational, and mental health], psychiatric services, in-home services, services in the local area, and transitional planning were cited as gaps by the five surveys.

The three remaining surveys were from two hospitals and an adult day health center program. The Laguna Honda Hospital and Rehabilitation Center was in the process of developing programming to address pre-vocational activities for TBI patients that could not be discharged because of lack of 24-hour supervision. This hospital cited the lack of resources with 24-hour supervision as a major barrier to transitioning TBI patients into the community. The hospital also cited funding for TBI support services as a significant gap.

The adult day health center cited two gaps in the service delivery system. The first was related to the need for more staff to provide the level of community assistance needed by TBI survivors to be fully integrated into the community. The second gap was related to the general lack of resources in rural areas.

#### **IV.4.4. Provider Surveys**

The eight-page provider survey was distributed through a list of 399 organizations and agencies. Some of the membership organizations on the list sent surveys to their constituencies. A total of 243 surveys were received from 220 providers. Thirteen surveys were removed from the database because the mission of the organization did not fit in with the purpose of the survey [e.g. nursing school or distance learning center] or the survey was blank. The database that was analyzed included 230 surveys from 207 providers. The analysis focused on the 207 providers. Multiple surveys received a provider were combined when they came from the same address. For example, the four surveys received from the Department of Rehabilitation Chico office were combined and counted as one response. The surveys received from the Department of Rehabilitation offices in Capitola and Sacramento were each counted as a provider.

For purposes of the analysis, the provider surveys were divided into two groups: inpatient services and community-based services. All of the surveys were included in the analysis of needs and service gaps. The analysis of specific inpatient services included only those hospitals that reported that they provided TBI services.

##### **IV.4.4.1. Geographic distribution of provider surveys**

<b>Table 19</b>			
<b>County</b>	<b>Inpatient</b>	<b>Community</b>	<b>Total</b>
Alameda	3	3	6
Butte		5	5
Colusa	1		1
Contra Costa	1	1	2
Fresno	3	2	5
Glenn	1		1
Humboldt	2	4	6
Imperial	2		2
Inyo	1		1
Kern	3		3
Kings	2		2
Los Angeles	37	4	41
Marin	1	1	2
Mendocino	1	2	3

Table 19			
Merced	2		2
Monterey	2		2
Napa	1	2	3
Nevada	1	1	2
Orange	14	9	23
Placer	3		3
Riverside	3	2	5
Sacramento	3	5	8
San Bernardino	5		5
San Diego	11	15	26
San Francisco	4	3	7
San Joaquin	2		2
San Mateo		3	3
Santa Barbara		2	2
Santa Clara	4	7	11
Santa Cruz	3	7	10
Solano	1		1
Sonoma	1		1
Stanislaus	1	2	3
Sutter	1		1
Tehama	1		1
Tulare	1		1
Ventura	3	2	5

#### IV.4.4.2. Provider characteristics – inpatient

Sixty percent [125] of the surveys were completed by hospitals that provide inpatient services. The responses were from hospitals located in 33 of the 58 counties. Half of the 125 responses were from hospitals located in Los Angeles [37], Orange [14] and San Diego [11] Counties. Eight of the 125 hospitals did not provide information beyond the fact that they provide inpatient services. Twenty-one other hospitals completed the surveys but reported that they did not provide services to individuals with TBI. All of the surveys were included in the analysis of other information such as defined service gaps. Table 20 summarizes the information provided by the 96 hospitals that provided services to individuals with TBI.

Table 20		
Services	Number	Hospital County
Inpatient	96	Alameda, Contra Costa, Fresno, Glenn, Humboldt, Imperial, Kern, Kings, Los Angeles, Marin, Monterey, Napa, Nevada, Orange, Placer, Riverside, Sacramento, San Bernardino, San Diego, San Francisco, San Joaquin, Santa Clara, Santa Cruz, Solano, Stanislaus, Sutter, Tehama, Tulare, and Ventura
Inpatient rehabilitation	57	Alameda, Contra Costa, Fresno, Humboldt, Kern, Los Angeles, Marin, Napa, Orange, Placer, Riverside, Sacramento, San Bernardino, San Diego, San Francisco, San Joaquin, Santa Clara, Santa Cruz, Solano, Tulare, and Ventura
Inpatient nursing facility	19	Alameda, Fresno, Los Angeles, Orange, Riverside, Sacramento, San Bernardino, San Diego, San Francisco, San Joaquin, Santa Clara, Santa Cruz, Tulare, Ventura
Outpatient rehabilitation	58	Alameda, Fresno, Humboldt, Kern, Los Angeles, Marin, Napa, Nevada, Orange, Placer, Riverside, Sacramento, San Bernardino, San Diego, San Francisco, San Joaquin, Santa Clara, Santa Cruz, Solano, Tulare, and Ventura
Community-based service	32	Contra Costa, Fresno, Humboldt, Kern, Los Angeles, Orange, San Bernardino, San Diego, San Francisco, San Joaquin, Santa Clara, Santa Cruz, Tulare, and Ventura
Provide services to TBI [General question]	96	Alameda, Contra Costa, Fresno, Glenn, Humboldt, Imperial, Kern, Kings, Los Angeles, Marin, Monterey, Napa, Nevada, Orange, Placer, Riverside, Sacramento, San Bernardino, San Diego, San Francisco, San Joaquin, Santa Clara, Santa Cruz, Solano, Stanislaus, Sutter, Tehama, Tulare, and Ventura
Have TBI program with experienced TBI staff	31	Alameda, Contra Costa, Los Angeles, Marin, Orange, Placer, Sacramento, San Bernardino, San Diego, San Francisco, Santa Clara, Santa Cruz, Solano, and Tulare
Work exclusively with individuals with TBI	12	Alameda, Los Angeles, Orange, San Diego, San Francisco, and Tulare
Have TBI component with staff who have experience with TBI	37	Alameda, Contra Costa, Humboldt, Kern, Los Angeles, Marin, Napa, Nevada, Orange, Placer, San Diego, San Francisco, Santa Clara, Santa Cruz, Solano, Stanislaus, and Tulare
Provide TBI services but no distinct TBI program	39	Alameda, Fresno, Glenn, Humboldt, Kern, Los Angeles, Marin, Placer, Riverside, Sacramento, San Bernardino, San Diego, San Joaquin, Santa Clara, Santa Cruz, Solano, Sutter, and Ventura

Table 20		
Have designated experienced staff to work on TBI issues	53	Alameda, Contra Costa, Humboldt, Kern, Los Angeles, Marin, Monterey, Napa, Nevada, Orange, Placer, Riverside, Sacramento, San Bernardino, San Diego, San Francisco, Santa Clara, Santa Cruz, Solano, Stanislaus, Tulare and Ventura
Offer education/training programs to others who are not staff	42	Alameda, Contra Costa, Kern, Los Angeles, Marin, Monterey, Orange, Placer, Sacramento, San Bernardino, San Diego, San Francisco, Santa Clara, Santa Cruz, Solano, Tulare and Ventura
Linguistically, culturally competent service delivery	85	Alameda, Contra Costa, Fresno, Glenn, Humboldt, Imperial, Kern, Kings, Los Angeles, Marin, Monterey, Napa, Orange, Placer, Riverside, Sacramento, San Bernardino, San Diego, San Francisco, San Joaquin, Santa Clara, Santa Cruz, Solano, Stanislaus, Sutter, Tehama, Tulare, and Ventura
Provide financial assistance	24	Alameda, Los Angeles, Monterey, Orange, San Diego, San Francisco, San Joaquin, and Santa Cruz
Provide rehabilitation services	88	Alameda, Contra Costa, Fresno, Humboldt, Imperial, Kern, Los Angeles, Marin, Monterey, Napa, Nevada, Orange, Placer, Riverside, Sacramento, San Bernardino, San Diego, San Francisco, San Joaquin, Santa Clara, Santa Cruz, Solano, Sutter, Tehama, Tulare, and Ventura
Provide long term community support	40	Alameda, Contra Costa, Fresno, Humboldt, Los Angeles, Napa, Orange, Placer, San Bernardino, San Diego, San Francisco, Santa Clara, Santa Cruz, Sutter, Tulare, and Ventura
Provide vocational services	33	Alameda, Contra Costa, Humboldt, Los Angeles, Monterey, Orange, Placer, San Bernardino, San Diego, San Francisco, San Joaquin, Santa Clara, and Santa Cruz

#### IV.4.4.3. Provider characteristics – community-based services

There were 82 surveys from providers of a wide range of community-based services. Thirty-four of the service providers were discussed in previous sections. There were three surveys from Department of Rehabilitation, a regional center, a regional center supported living vendor, a TBI project site, 11 independent living centers, nine caregiver resource centers, seven community colleges, and a four-year college.

The 47 remaining provider surveys are shown on Table 21 by their principle service.

Table 21
----------

Service	Number	County
Adult Day Health Program	3	Butte, Orange and Santa Cruz Counties
Advocacy	1	Statewide
Ambulatory Health Clinic	1	Humboldt County
Brain injury support organization	1	San Diego County
Care/case Manager	3	San Diego [2] and Santa Cruz Counties
Clubhouse	1	Orange County
Community reintegration	3	Humboldt and Los Angeles [2] Counties
Easter Seals programs	3	Fresno, Sacramento and Ventura Counties
Home Health Agency	2	Butte and San Diego Counties
Homeless program	1	Santa Cruz County
Outpatient mental health clinic	3	Alameda, Santa Clara and San Diego Counties
Private practice neurology	1	San Diego County
Private practice neuropsychology	2	Orange and San Diego Counties
Private practice speech/language	1	San Diego County
Recreation	4	San Mateo, Santa Clara [2] and Nevada Counties
Rehabilitation	1	Orange County
Senior center	1	Humboldt County
Socio-sexual education	1	San Diego County
Stroke program	2	Riverside and Santa Clara Counties
Support group	7	Alameda, Butte, Contra Costa, Fresno, Sacramento, San Diego and San Mateo Counties
Supported living	1	Santa Clara County
Vocational services	4	Orange [2] and Santa Clara [2] Counties

#### IV.5. Service Development in the State

The provider survey asked respondents to describe how well various services were developed currently in their geographic area of California. Services were rated on a scale of 1 to 5 with 1 being poorly developed, 3 being adequate, and 5 being very well developed. Table 21 aggregates the data for the 191 provider surveys that included ratings for one or more services.

The second average score was calculated by dividing the total average score for the counties by the number of counties. The detail by county is shown in Appendix 10.

The surveys rate the post injury services as the least well developed in the state. On average, no service, including inpatient care is rated higher than adequate.

<b>Table 21</b>		
<b>Service</b>	<b>Number of Counties</b>	<b>Average Score</b>
Programs for prevention of brain injury	38	1.7
Emergency, medical and hospital care for person with brain injury	38	3.0
Rehabilitation services for persons with traumatic brain injury	38	2.7
Public programs and services in the community for children and adolescents with traumatic brain injury	37	1.9
Public programs and services in the community for adults with traumatic brain injury	38	1.9
Elementary education services in schools for students with traumatic brain injuries	38	1.9
Secondary education services in schools for students with traumatic brain injuries	38	1.9
Vocational services for persons with traumatic brain injury	38	1.8
Community supports for persons with traumatic brain injury	38	1.7
Long term funding for lifelong needs	38	1.5
Assisted living options for persons with traumatic brain injury	38	1.6



# APPENDIX 1

Comparison of Geographic Distribution of Injuries				
Counties	TBI Surveys		1998 Surveillance Data	
	Number	Percent	Number	Percent
<b>Total</b>	<b>657</b>	<b>100%</b>	<b>22,711</b>	<b>100%</b>
Alameda	10	2%	1152	5%
Alpine			1	0%
Amador	3	0%	35	0%
Butte	20	3%	152	1%
Calaveras			35	0%
Colusa			24	0%
Contra Costa	11	2%	708	3%
Del Norte			20	0%
El Dorado	1	0%	88	0%
Fresno	11	2%	432	2%
Glenn	1	0%	22	0%
Humboldt	23	4%	98	0%
Imperial			110	0%
Inyo			9	0%
Kern	10	2%	356	2%
Kings			72	0%
Lake			41	0%
Lassen			7	0%
Los Angeles	106	16%	5854	26%
Madera	2	0%	66	0%
Marin	10	2%	116	1%
Mariposa			15	0%
Mendicino			62	0%
Merced	1	0%	100	0%
Modoc			3	0%
Mono			0	0%
Monterey	1	0%	211	1%
Napa	5	1%	64	0%
Nevada			84	0%

**APPENDIX 1**

<b>Comparison of Geographic Distribution of Injuries</b>				
<b>Counties</b>	<b>TBI Surveys</b>		<b>1998 Surveillance Data</b>	
	<b>Number</b>	<b>Percent</b>	<b>Number</b>	<b>Percent</b>
Orange	131	20%	1848	8%
Placer	3	0%	173	1%
Plumas			17	0%
Riverside	6	1%	1101	5%
Sacramento	39	6%	945	4%
San Benito	3	0%	26	0%
San Bernardino	6	1%	1266	6%
San Diego	40	6%	2596	11%
San Francisco	5	1%	491	2%
San Joaquin			311	1%
San Luis Obispo	7	1%	151	1%
San Mateo	6	1%	375	2%
Santa Barbara	13	2%	215	1%
Santa Clara	65	10%	943	4%
Santa Cruz	50	8%	119	1%
Shasta	7	1%	123	1%
Sierra			4	0%
Siskiyou			17	0%
Solano	7	1%	242	1%
Sonoma	1	0%	340	1%
Stanislaus	11	2%	320	1%
Sutter			60	0%
Tehama	2	0%	36	0%
Trinity			20	0%
Tulare	3	0%	197	1%
Tuolumne	3	0%	58	0%
Ventura	18	3%	359	2%
Yolo			100	0%
Yuba			57	0%
Unknown	16	2%	264	1%

## Appendix 2

Living Options														
Living With	T		P		G		Transitional		Nursing/LTC		U		O	
	#	S	#	S	#	S	#	S	#	S	#	S	#	S
Survivor alone	1	1	131	103	1	1	2	0			1	0	7	5
Survivor and one other choice														
Children <21	1	1	17	10	1	0								
Spouse/partner	1	1	119	101							1	0	3	0
Parent	1	1	158	115			1	0					3	0
Other relative	2	1	23	16										
Friend/housemate	6	4	44	40	8	5	2	1	9	2	2	0	1	1
Personal aide	2	1	16	8	7	4	3	2	2	1			1	1
Survivor and two other choices														
Spouse/partner and children <21	3	2	30	23									2	1
Spouse/partner and other relative	3	1	2	1	1	1								
Spouse/partner and friend/housemate	3	2	2	1			1	1						
Spouse/partner and parent	1	0									1	0		
Children <21 and friend/housemate	2	2	2	2										

Living Options												
Living With	Total		Private		Group Home		Transitional		Nursing/LTC	Unstable	Other	
	#	Satisfied	#	Satisfied	#	Satisfied	#	Satisfied	#	Satisfied	#	Satisfied
Children <21 and other relative	1	1	1	1								
Children <21 and other	1	1	1	1								
Parent and children <21	1	1	10	10								
Parent and other relative	1	9	11	9								
Parent and friend/housemate	2	2	2	2								
Parent and personal aide	2	2	2	2								
Friend/housemate and personal aide	6	4	1		5	4						
Friend/housemate and other	2	0			1	0			1	0		
Survivor and three other choices												
Spouse/partner, children <21 and aide	1	1	1	1								
Friend/housemate and personal aide	1	1			1	1						
Parent, children <21 and friend/housemate	1	1	1	1								
Parent, children <21 and other	1	1	1	1								
Parent, children <21 and other relative	1	1	1	1								

## Appendix 2

Living Options														
Living With	Total		Private		Group Home		Transitional		Nursing/LTC		Unstable		Other	
	#	Satisfied	#	Satisfied	#	Satisfied	#	Satisfied	#	Satisfied	#	Satisfied	#	Satisfied
Parent, other relative and other	2	2	2	2										
Parent, other relative and friend/housemate	1	0	1	0										
Parent, other relative and personal aide	1	1	1	1										
Other	5	3	3	1	20	14	3	2	24	13			4	3
Blank	5	4	4	4									1	0
Total	7	5	5	4	4	3	1	6	3	1	5	0	2	1
Percent Total	1	1	83%	8	6%	6	2%	1	5%	3	1%	0	3%	2

## Appendix 3

Transportation Combinations		
	Number	Percent
Walk/wheelchair/bike/drive/ride with family/friends/special disability transportation	1	0%
Walk/wheelchair/bike/drive/ride with family/friends	1	0%
Walk/wheelchair/bike/drive	1	0%
Walk/wheelchair/bike/ride with family/friends/bus/special disability transportation	1	0%
Walk/wheelchair/bike/ride with family/friends	1	0%
Walk/wheelchair/ride with family/friends/bus	2	0%
Walk/wheelchair/ride with family/friends/special disability transportation	4	1%
Walk/wheelchair/ride with family/friends	3	0%
Walk/wheelchair/special disability transportation	1	0%
Walk/bike/drive/ride with family/friends/bus/special disability transportation	1	0%
Walk/bike/drive/ride with family/friends/bus/other	1	0%
Walk/bike/drive/ride with family/friends/bus	11	2%
Walk/bike/drive/ride with family/friends	15	2%
Walk/bike/drive/bus	7	1%
Walk/bike/drive	11	2%
Walk/bike/ride with family/friends/bus/special disability transportation	7	1%
Walk/bike/ride with family/friends/bus/other	2	0%
Walk/bike/ride with family/friends/bus	18	3%
Walk/bike/ride with family/friends/special disability transportation	6	1%
Walk/bike/ride with family/friends	6	1%
Walk/bike/bus	3	0%
Walk/bike/special disability transportation	3	0%
Walk/drive/ride with family/friends/bus/special disability transportation	3	0%
Walk/drive/ride with family/friends/bus/other	5	1%

## Appendix 3

Transportation Combinations		
	Number	Percent
Walk/drive/ride with family/friends/bus	9	1%
Walk/drive/ride with family/friends/other	2	0%
Walk/drive/ride with family/friends	41	6%
Walk/drive/bus/special disability transportation	1	0%
Walk/drive/bus	4	1%
Walk/drive/special disability transportation	3	0%
Walk/drive	29	4%
Walk/ride with family/friends/bus/special disability transportation	13	2%
Walk/ride with family/friends/bus	50	7%
Walk/ride with family/friends/special disability transportation/other	1	0%
Walk/ride with family/friends/special disability transportation	28	4%
Walk/ride with family/friends/other	4	1%
Walk/ride with family/friends	49	7%
Walk/bus/special disability transportation	5	1%
Walk/bus/other	3	0%
Walk/bus	21	3%
Walk/special disability transportation	6	1%
Walk/other	1	0%
Walk	7	1%
Wheelchair/drive/ride with family/friends	1	0%
Wheelchair/ride with family/friends/bus/special disability transportation	2	0%
Wheelchair/ride with family/friends/special disability transportation/other	2	0%
Wheelchair/ride with family/friends/special disability transportation	17	2%
Wheelchair/ride with family/friends/other	3	0%

## Appendix 3

Transportation Combinations		
	Number	Percent
Wheelchair/ride with family/friends	17	2%
Wheelchair/bus/special disability transportation	7	1%
Wheelchair/special disability transportation/other	1	0%
Wheelchair/special disability transportation	6	1%
Wheelchair/other	2	0%
Wheelchair	17	2%
Bike/drive/ride with family/friends	1	0%
Bike/drive/bus	1	0%
Bike/drive	3	0%
Bike/ride with family/friends/bus/special disability transportation	1	0%
Bike/ride with family/friends/bus	2	0%
Bike/ride with family/friends	2	0%
Bike/bus	2	0%
Drive/ride with family/friends/bus	1	0%
Drive/ride with family/friends/special disability transportation	2	0%
Drive/ride with family/friends	18	3%
Drive/bus	3	0%
Drive/special disability transportation	1	0%
Drive/other	1	0%
Drive	47	7%
Ride with family/friends/bus/special disability transportation/other	1	0%
Ride with family/friends/bus/special disability transportation	3	0%
Ride with family/friends/bus/other	1	0%
Ride with family/friends/bus	6	1%



## Appendix 3

Transportation Combinations		
	Number	Percent
Ride with family/friends/special disability transportation/other	5	1%
Ride with family/friends/special disability transportation	23	3%
Ride with family/friends/other	3	0%
Ride with family/friends	67	10%
Bus/special disability transportation/other	2	0%
Bus/special disability transportation	2	0%
Bus	2	0%
Special disability transportation	15	2%
Other	12	2%
Total	689	100%

## Post Injury Family Life

	Agree		Disagree		Neutral	
	Number	Percent	Number	Percent	Number	Percent
<b>Financial Impact</b>						
Finances have been a problem for the family as a result of the injury.	79	67%	15	13%	23	19%
Income has been lost due to time out of work because of the family member's injury.	80	68%	23	19%	14	12%
Family member[s] had to leave job or reduce work activities to meet care-giving duties.	73	62%	26	22%	16	14%
Additional income is needed in order to cover injury-related expenses.	64	54%	32	27%	21	18%
The family has refused a transfer or new position because of family member's injury.	19	16%	58	49%	37	31%
Family has had unexpected expenses because of needed home modifications.	31	26%	55	47%	29	25%
Retirement plans have been put on hold because of the family member's injury.	45	38%	42	36%	30	25%
<b>Hired Assistance</b>						
Staff has been hired to assist with the care of my family member.	36	31%	55	47%	21	18%
Finding trained staff is relatively easy.	8	7%	57	48%	45	38%
Hired staff is dependable.	17	14%	41	35%	50	42%
I would use hired assistance for my family member if insurance or other funding source paid.	60	51%	9	8%	39	33%

## Post Injury Family Life

	Agree		Disagree		Neutral	
	Number	Percent	Number	Percent	Number	Percent
<b>Future Expectations</b>						
I do not expect many changes or improvements in my family member anymore.	52	44%	41	35%	23	19%
I will always be responsible for managing my family member's care.	69	58%	14	12%	33	28%
My family member will be able to live independently in the community.	42	36%	51	43%	23	19%
I worry about who will take over when I am no longer able, or when I die.	79	67%	19	16%	18	15%
Our family has discussed the future but is unsure of what to do.	70	59%	23	19%	21	18%
<b>Quality of Life</b>						
Members of the family have left due to stress.	31	26%	58	49%	27	23%
Family members have returned home to help take care of the injured person.	14	12%	70	59%	30	25%
Our social life has changed since the injury.	90	76%	14	12%	12	10%
Friends and family visit less often.	80	68%	20	17%	16	14%
I am satisfied with my life.	30	25%	50	42%	37	31%
Some days I feel like I am unable to cope any longer.	56	47%	34	29%	24	20%
My family member behaves in ways that cause considerable problems for others and for me.	65	55%	32	27%	19	16%

## Post Injury Family Life

	Agree		Disagree		Neutral	
	Number	Percent	Number	Percent	Number	Percent
<b>Supports</b>						
I feel our family could benefit from counseling to help cope with life changes.	69	58%	20	17%	24	20%
It would be helpful to meet with other families for support.	66	56%	19	16%	28	24%
I feel that there are adequate services in my community for individuals who have brain injury.	16	14%	83	70%	15	13%
I need some type of relief care or respite from daily responsibilities.	47	40%	36	31%	32	27%
It is difficult to get help from family and friends.	48	41%	41	35%	25	21%
My private insurance/HMO has been helpful in meeting my family member's needs.	31	26%	55	47%	29	25%
<b>Relationships</b>						
My relationship with my spouse/significant other has become more stressful.	71	60%	21	18%	23	19%
I do not have enough time to spend with my non-disabled child/children.	39	33%	27	23%	44	37%
I have avoided pursuing new relationships since my family member's injury	39	34%	28	24%	46	39%
Relationships in our family are stronger since the injury.	48	41%	34	29%	33	28%
My relationships with other family members have become more stressed.	52	44%	33	28%	29	25%

Post Injury Family Life						
	Agree		Disagree		Neutral	
	Number	Percent	Number	Percent	Number	Percent
<b>Gathering Information</b>						
Information regarding brain injury and services has been readily available.	38	32%	61	52%	17	14%
I feel I have enough knowledge regarding brain injury.	36	31%	60	51%	22	19%
I understand Federal and state financial benefits and programs available for my family member.	22	19%	72	61%	23	19%

Advisory Board Focus Group		
Current TBI service delivery system	What is working in current system	Future TBI service delivery system
<b>Structure</b> <ul style="list-style-type: none"> <li>→ Almost non-existent</li> <li>→ Fragmented</li> <li>→ Horrible</li> <li>→ Inadequate</li> <li>→ Inhumane</li> <li>→ Just beginning</li> <li>→ Lack of Pediatric services</li> <li>→ Lacks funding</li> <li>→ Lessons learned not passed on to help others</li> <li>→ Limited resources</li> <li>→ Neglected</li> <li>→ Poor, mediocre</li> <li>→ Restrictive/ed</li> <li>→ Under educated</li> <li>→ Unfair</li> <li>→ Untouchable</li> </ul>	<b>Structure</b> <ul style="list-style-type: none"> <li>→ Acknowledgement of cultural needs and practices</li> <li>→ Agency networking and collaboration</li> <li>→ Coastline Community College provides individualized service and accepts you for who you are, you are and lets you know that you are not alone</li> <li>→ Cognitive retraining at Coastline Community College</li> <li>→ Committed professional staff –tied to personal experiences</li> <li>→ Developing network and open lines of communication</li> <li>→ Entitlement program under DDS –for children</li> <li>→ Excellent pockets of service</li> <li>→ Gets us networking [grassroots]</li> <li>→ Have Advisory Board</li> <li>→ Improvement in working with Department of Rehabilitation</li> <li>→ Leadership at State level</li> <li>→ On the move</li> <li>→ Passionate, creative, willing caregivers and service providers</li> <li>→ Positive reinforcement and focus</li> <li>→ Provider to provider connections</li> <li>→ Some inroads with insurance companies/HMO's to cover services.</li> <li>→ Ventura College Disabled Student Services [not available in every community college]</li> </ul>	<b>Structure</b> <ul style="list-style-type: none"> <li>→ <b>Advocacy in all services</b></li> <li>→ Advocacy to State policy makers</li> <li>→ Case management</li> <li>→ Continuum for education</li> <li>→ Creation of a California Department of Traumatic Brain Injury</li> <li>→ Day and residential programs</li> <li>→ Develop a set of strategies to implement and tactics</li> <li>→ <b>Funding</b></li> <li>→ Implement matrix management</li> <li>→ Improve the tie between insurance companies and providers [definition of services necessary for TBI and a link to insurance company and services]</li> <li>→ Income levels</li> <li>→ Long term perspective</li> <li>→ More collaboration between existing providers.</li> <li>→ More community college on-site programs [they recognize the need for ongoing programs]</li> <li>→ Ongoing support for survivors, families and providers</li> <li>→ Qualitative and quantitative analysis of the problem</li> <li>→ Rural and urban services</li> <li>→ Transportation</li> <li>→ Ways to connect beginning of continuum to end</li> </ul>

Advisory Board Focus Group		
Current TBI service delivery system	What is working in current system	Future TBI service delivery system
<b>Awareness of the system/TBI</b> → Invisible → Low awareness → Unaccepted → Unknown	<b>Awareness of the system/TBI</b> → Building support in families – ripple effect → Community education and information → Makes a huge difference when providers know about TBI → Technology advances/WEB resources	<b>Awareness of the system/TBI</b> → Basic education on the nature of TBI → Caregivers need to be educated and oriented to the needs and challenges of TBI. → Cultural competence in materials → <b>Education</b> → Marketing successes to legislature and others → Public and professional awareness including insurance companies
<b>Survivors and families</b> → Burn out → Demoralizing → Discrimination → Dumps on families → Exhausting → Frustrating → Hard work → Makes angry → Not meeting needs	<b>Survivors and families</b> → Caregiver and provider compassion → Family to family connections → Individual to individual connections → Now have possibilities → Proving that TBI survivors are not useless → Survivor's determination to get better/recover → TBI experience provides growth experience → TBI experience takes you to new places/people → Tenacity of survivors, caregivers and providers	<b>Survivors and families</b> → Recognition of cost to the families

## Appendix 6

	Services and Supports				Needs		Receives	
	Needs	Receives	Needs	Receives	Total	Percent	Total	Percent
<b>Cognitive/emotional support</b>								
Controlling his/her temper	49	33	172	164	221	33%	197	29%
Expressing needs/understanding others	51	28	211	168	262	39%	196	29%
Fulfilling needs for intimacy	42	19			42	35%	19	16%
Improving his/her memory, solving problems better	64	29	260	189	324	48%	218	32%
Improving his/her mood	54	35	213	172	267	39%	207	30%
Managing stress/emotional upsets	53	40	234	181	287	42%	221	33%
<b>Community life</b>								
Feeling part of community	43	26	197	137	240	35%	163	24%
Finding places and opportunities to socialize	54	30	264	142	318	47%	172	25%
Participating in religious services or spiritual programs	25	39	100	179	125	18%	218	32%
Participating in sports/recreation	48	24	200	118	248	36%	142	21%
Traveling in community	30	51			30	25%	51	43%
<b>Employment/training and income</b>								
Finding paid employment	57	10	254	74	311	46%	84	12%
Increasing educational qualifications	55	20	235	129	290	43%	149	22%
Increasing income	59	13	317	96	376	55%	109	16%
Training in community to increase/improve job skills	64	13	256	154	320	47%	167	25%
<b>Housing</b>								
Finding housing that is affordable and accessible	35	28	192	149	227	33%	177	26%
<b>Health/therapy issues</b>								
Controlling alcohol and/or drug use	11	21	39	112	50	7%	133	20%



## Appendix 6

Services and Supports								
	Needs	Receives	Needs	Receives	Needs		Receives	
Improving his/her health	36	39	175	197	211	31%	236	35%
Increasing independence in walking, lifting and balancing	21	40	147	155	168	25%	195	29%
Monitoring effects of medication	18	51			18	15%	51	43%
Monitoring health problems	19	51			19	16%	51	43%
Personal assistance								
Caring for children	7	11	57	72	64	9%	83	12%
Getting assistance with reading/correspondence	27	42			27	23%	42	35%
Handling legal problems	43	27	163	164	206	30%	191	28%
Increasing independence in eating, dressing, bathing, etc.	16	42	83	176	99	15%	218	32%
Increasing independence in housekeeping, cooking, etc.	35	30	176	176	211	31%	206	30%
Managing his/her money, paying bills	35	47	140	240	175	26%	287	42%
Obtaining personal care attendant	25	38	135	166	160	24%	204	30%
Services/supports								
Connecting with resources	59	30			59	49%		
Coordinating services received	49	30	183	166	232	34%	196	29%
Obtaining equipment [computers, wheelchairs, etc.]	31	23	134	128	165	24%	151	22%
	Overall Satisfaction With Services							
	Family		Survivor		Total			
Overall service	Yes	No	Yes	No	Yes		No	
Getting needed services	55	69	336	247	391	55%	316	45%
Satisfaction with services	57	67	341	242	398	56%	309	44%

Survivor and Family Survey Comments Regarding Service Needs [Total surveys = 389]	
Comments services	Number
Advocacy	17
Advocacy with HMO	2
Advocacy with social security/Medi-Cal/Medicare	8
Better enforcement of rights with service agencies	1
Fair treatment	2
Help with IEP	1
Make ADA work for instead of against TBI/TBI recognized disability	4
Rights	2
Town become more wheel chair accessible	1
<b>Case management/service coordination</b>	<b>37</b>
Agency that specializes in TBI to coordinate services	4
Case management/service coordination	18
Futures planning	15
<b>Counseling</b>	<b>21</b>
Anger management group or counseling	2
Counseling	13
Family counseling	2
Long term counseling	1
Marriage counseling	2
Mental health counseling	1
<b>Day program/activities</b>	<b>17</b>
Clubhouses	2
Creative endeavors/meaningful tasks	2
Day care	4
Day program	4
Day program for younger adults	1
Something to keep busy	1
Volunteer opportunities	3

Comments services	Number
<b>Educational services</b>	<b>35</b>
1:1 Tutoring/reader	3
Accessible local TBI courses	2
Basic educational skills	3
Classes to learn more	3
Dictionaries	1
Replicate community college brain injury courses	15
Support to continue education beyond high school	6
Tutoring for children	2
<b>Employment</b>	<b>47</b>
Employment	24
Competent vocational counseling	2
Department of Rehabilitation employment services	1
Job finding and follow-up	6
More hours	1
Supported employment	1
Training in job skills	12
<b>Equipment</b>	<b>5</b>
Computer/programs	4
Equipment	1
<b>Financial/legal assistance</b>	<b>60</b>
Assistance with cost of care/services/prescriptions	5
Additional income	8
Change in Medi-Cal/Social security eligibility for employed	3
Day care costs	1
Financial assistance	12
Financial assistance with medical insurance	3
Funding for TBI	2
Legal	10
Money management, budgeting and financial planning	4
Obtain or restore SSI benefits/Medi-Cal/Medi-care	11

SSI should be less restrictive	1
Comments services	Number
<b>Housing</b>	<b>80</b>
Accessible housing	3
Affordable group homes for TBI	9
Affordable housing	29
Affordable long term care facilities	4
Appropriate housing	6
Assisted Living	3
Better housing	2
Center for Independent Living	1
Housing for people between 18 and 25	1
Housing near family	2
Independent living arrangement with caretakers	3
Independent/supported living arrangement	9
Managed residential programs	2
Safe living situation	3
SNF dedicated to brain injury	1
Stimulating living arrangement with activities	1
Transitional living programs	1
<b>Information</b>	<b>43</b>
CA BIA better staffed and more responsive and reactivate website.	2
Complete information on injury/condition	2
Consistent information	1
Discharge planning would include all resources	2
Information on TBI, services and resources	27
List of caregivers for IHSS	1
Mental status and areas of improvement	1
Need brain injured network	2
One source for all information	1
Seminars	1
Website with all resource information	3

Comments services	Number
<b>Medical/psychological</b>	<b>22</b>
Affordable insurance coverage part for prescriptions	2
Assistance in getting medical services	2
Better doctors to explain injuries and realistically describe future	4
Better medication	1
Control temper/reduce stress/lose weight/stop smoking	1
Dental services	2
Hospital services	1
Improve physical condition	1
Improved mental cognition	1
Needs total nursing care	1
Psychiatric services	1
Psychological services	2
Standard medical protocol for TBI	1
Substance abuse services	2
<b>More dignified treatment from agencies and the public</b>	<b>25</b>
Treated with dignity and respect	4
Better pay for IHSS workers	2
Department of Rehabilitation not helpful/services nonexistent/slow	9
Easier access to funded programs	2
Focus on abilities/skills	1
Less red tape	2
Monitoring of programs that are funded that turn people away	1
Social services should be nicer and more user friendly	4
<b>Other</b>	<b>18</b>
A better system	1
A chance to succeed	2
A miracle	1
Better myself	1
Education/Anything that would help be productive	2
Go on vacation by myself	1
Help in developing a business idea	1

Comments services	Number
<b>Other continued</b>	
Help to learn to live with limitations	2
Left arm replacement	1
Personalized treatment	1
Pet	1
Research	1
See children	1
Someone to say they were sorry after accident	1
Tickets to events	1
<b>Personal assistance</b>	<b>14</b>
Reliable personal aide	8
Part time personal assistance	1
Cleaning service	1
Assistance with paperwork	4
<b>Public/professional awareness and education</b>	<b>42</b>
Education for HMOs	2
Education for law enforcement/courts	2
Education for medical and other professional	11
Education of Department of Rehabilitation counselors	2
Employers need to be trained	4
Outreach	1
Public awareness and education	19
Train job coaches and others on TBI	1
<b>Skills training</b>	<b>14</b>
Interpersonal skill training	2
Activities of daily living	1
Communication skills	4
Compensatory skills training to multi task and/or handle situations of life	2
Coping skills	2
Public speaking	1
Skills improvement	2

Comments services	Number
<b>Social/recreation</b>	<b>47</b>
Activities	14
Accessible social activities	1
Activities in area	1
Affordable social opportunities	2
Art class	1
Friends/opportunity to meet friends	4
Group activities	1
Horse jumping lessons	1
Local travel agency that works for disabled	1
Music lesson	2
Recreation opportunities	10
Relationship	5
See family more often	1
Supervised activities	1
Yoga	2
<b>Services/support</b>	<b>103</b>
Affordable independent living services	1
Affordable programs	4
Assistance in becoming independent	10
Assistance no matter what age of onset	1
Assistance to find care/services when health insurance ends	4
Assistive living services	1
Available throughout state	1
Brain injury network system to get all type of supports	1
Crisis intervention	2
Early intervention and assistance	3
General assistance with the effects of TBI for survivor and family	1
Health club	1
Help with stress and mood	2
Help and support /all services/not just referrals	11

Improve memory	10
Comments services	Number
<b>Services/support continued</b>	
In home services	10
Long term services and support	3
Monitoring and assessment of service effectiveness	2
More attendant care hours from IHSS	1
More opportunity to shower [lives in LTC]	1
More public programs	1
More service options	2
Needs all services	1
Programs for people without resources	1
Regional center services	5
Respite	11
Services for blind survivors	2
Services for high functioning survivors	1
Services for mild TBI	2
Services/supports for minors	1
Services/supports provided by people trained in TBI	4
Substance abuse	2
<b>Support groups</b>	<b>32</b>
Support groups	17
Age appropriate support groups	1
Local survivor and caregiver support groups	4
Single gender support groups	2
Spouse/partner support groups	1
Support group dealing with self esteem and mood management	3
Support group for emotional issues	2
Support groups for each stage of recovery	1
Tape recorded support group for caregiver	1
<b>Therapy</b>	<b>46</b>
Balancing and walking	3
Occupational therapy	3



Physical therapy	20
Comments services	Number
<b>Therapy continued</b>	
Pool therapy	1
Rehabilitation	8
Speech therapy	8
Unspecified therapy	3
<b>Training</b>	<b>9</b>
Caregiver training	3
Computer	3
Learn to cook and plan proper meals	2
Learn to cook for large groups	1
<b>Transportation</b>	<b>35</b>
Reliable transportation	6
Assistance in obtaining and accessing transportation	1
Better transportation for disabled	2
Door to door	1
Driver	1
Drivers license	9
Drivers training	3
Eligibility for paratransit	2
Identification card	2
Improved bus service	2
Mobility training	1
User friendly paratransit	4
Vehicle	1
<b>Total Comments</b>	<b>790</b>

## Family Survey Ratings

	Strongly Agree		Agree		Neutral		Disagree		Strongly Disagree		Don't Know	
	#	%	#	%	#	%	#	%	#	%	#	%
<b>California Brain Injury Association Services</b>												
Easily available	5	4%	22	18%	12	10%	19	16%	9	7%	50	41%
Capable/skilled	5	4%	21	17%	19	16%	6	5%	4	3%	63	52%
Consistent and dependable	4	3%	14	11%	19	16%	8	7%	4	3%	64	52%
Provided in a timely manner	6	5%	12	10%	18	15%	11	9%	5	4%	66	54%
<b>Center for Independent Living Services</b>												
Easily available	5	4%	15	12%	5	4%	16	13%	10	8%	64	52%
Capable/skilled	4	3%	12	10%	12	10%	9	7%	7	6%	71	58%
Consistent and dependable	5	4%	12	10%	10	8%	8	7%	7	6%	72	59%
Provided in a timely manner	5	4%	11	9%	8	7%	10	8%	8	7%	72	59%
<b>Caregiver Resource Center Services</b>												
Easily available	10	8%	15	12%	11	9%	14	11%	9	7%	56	46%
Capable/skilled	8	7%	14	11%	11	9%	9	7%	7	6%	64	52%
Consistent and dependable	6	5%	14	11%	11	9%	9	7%	8	7%	65	53%
Provided in a timely manner	7	6%	12	10%	12	10%	9	7%	7	6%	67	55%
<b>Educational Services</b>												
Adequately addressing needs	4	3%	17	14%	13	11%	20	16%	17	14%	47	39%
Easily available	3	2%	16	13%	16	13%	21	17%	15	12%	47	39%
Capable/skilled	7	6%	16	13%	21	17%	9	7%	6	5%	57	47%
Consistent and dependable	4	3%	14	11%	18	15%	11	9%	8	7%	57	47%
Provided in a timely manner	3	2%	14	11%	17	14%	13	11%	9	7%	57	47%
<b>Employment Services for Person with TBI</b>												
Easily available	1	1%	5	4%	11	9%	16	13%	28	23%	55	45%
Capable/skilled	1	1%	4	3%	15	12%	12	10%	21	17%	62	51%
Consistent and dependable	1	1%	4	3%	14	11%	11	9%	24	20%	61	50%
Provided in a timely manner	1	1%	5	4%	11	9%	12	10%	24	20%	62	51%
<b>Home Services through IHSS</b>												
Easily available	6	5%	9	7%	7	6%	7	6%	11	9%	75	61%
Capable/skilled	6	5%	8	7%	7	6%	4	3%	6	5%	84	69%
Consistent and dependable	5	4%	7	6%	12	10%	2	2%	6	5%	83	68%
Provided in a timely manner	6	5%	7	6%	10	8%	3	2%	8	7%	81	66%
<b>Private Pay Personal Care Attendant Services</b>												
Easily available	2	2%	12	10%	8	7%	10	8%	12	10%	71	58%
Capable/skilled	2	2%	7	6%	10	8%	8	7%	9	7%	79	65%
Consistent and dependable	2	2%	5	4%	12	10%	6	5%	10	8%	80	66%
Provided in a timely manner	2	2%	4	3%	13	11%	7	6%	9	7%	79	65%

## Family Survey Ratings

	Strongly Agree		Agree		Neutral		Disagree		Strongly Disagree		Don't Know	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
<b>Housing Services [subsidized supported, etc.]</b>												
Easily available	2	2%	2	2%	5	4%	14	11%	31	25%	62	51%
Affordable	2	2%	1	1%	7	6%	13	11%	29	24%	65	53%
Adequately addressing needs	2	2%	3	2%	4	3%	10	8%	32	26%	64	52%
Consistent and dependable	1	1%	2	2%	9	7%	6	5%	25	20%	71	58%
Provided in a timely manner	1	1%	2	2%	9	7%	5	4%	29	24%	68	56%
<b>Medicare or Medi-Cal</b>						0%						
Adequately covering medical needs	5	4%	14	11%	15	12%	19	16%	22	18%	30	25%
Easily accessed	5	4%	19	16%	11	9%	18	15%	20	16%	34	28%
Capable/skilled	5	4%	15	12%	16	13%	17	14%	13	11%	38	31%
Consistent and dependable	4	3%	18	15%	17	14%	14	11%	7	6%	35	29%
Provided in a timely manner	4	3%	20	16%	11	9%	21	17%	16	13%	33	27%
<b>Medical Rehabilitation Services</b>						0%						
Affordable	3	2%	9	7%	7	6%	26	21%	40	33%	30	25%
Adequately addressing the needs	3	2%	15	12%	8	7%	21	17%	34	28%	34	28%
Capable/skilled	6	5%	22	18%	17	14%	12	10%	19	16%	38	31%
Provided in a timely manner	5	4%	14	11%	16	13%	13	11%	25	20%	40	33%
<b>Nursing Home Services</b>												
Affordable	1	1%	2	2%	5	4%	10	8%	24	20%	71	58%
Adequately addressing the needs	1	1%	1	1%	4	3%	8	7%	23	19%	76	62%
Capable/skilled	1	1%	3	2%	8	7%	7	6%	16	13%	78	64%
Consistent and dependable	1	1%	1	1%	8	7%	7	6%	18	15%	78	64%
<b>Respite Care Services</b>												
Easily available	2	2%	11	9%	11	9%	10	8%	14	11%	76	62%
Capable/skilled	2	2%	12	10%	12	10%	3	2%	10	8%	85	70%
Consistent and dependable	2	2%	11	9%	11	9%	5	4%	11	9%	84	69%
Provided in a timely manner	2	2%	10	8%	10	8%	5	4%	13	11%	83	68%
<b>Social Security Services</b>												
Adequately converging the income needs	1	1%	6	5%	10	8%	25	20%	46	38%	27	22%
Easily available	2	2%	18	15%	12	10%	26	21%	31	25%	25	20%
Capable/skilled	2	2%	16	13%	24	20%	16	13%	21	17%	34	28%
Consistent and dependable	4	3%	24	20%	22	18%	12	10%	21	17%	30	25%
Provided in a timely manner	4	3%	26	21%	14	11%	14	11%	28	23%	29	24%
	199	3%	625	10%	666	10%	657	10%	926	14%	3329	52%

## Appendix 9

<b>Provider Survey Service Needs/Gaps</b> <b>[Total = 155 Surveys]</b>	
<b>Need/Gap</b>	<b>Number</b>
<b>Case Management</b>	<b>33</b>
Case management/service coordination	29
Comprehensive discharge planning	1
Futures planning	1
Specialized case management/multi-disciplinary resource team	2
<b>Counseling</b>	<b>6</b>
Accessible peer counseling/support/follow up	5
Counseling options	1
<b>Employment/day</b>	<b>76</b>
Adult day health care programs/funding for those without Medi-Cal	1
Better training for vocational opportunities	13
Clubhouses	1
Day programs for different ages/ levels of care	9
Day programs/rehabilitation/treatment	15
Home health programs	1
Job placement/tryouts/accommodations	9
Long term job coaching	5
Return to work transition services	2
Supported employment	6
TBI ADHC programs	2
Vocational opportunities	7
Vocational training for indigent	1
Volunteer opportunities	4
<b>Funding/Benefits</b>	<b>31</b>
Coordination of benefits	1
Decrease time it takes to get into publicly funded programs	1
Funding	12
Funding for continuum of care	1
Funding for Making Headway Inc.	1
Funding for provider	1
Funding for Rehabilitation without Walls assisted living	1
Funding for transitional living	2
Funding to develop new programs/services in community	2
Funding to provide equipment	1
Insurance to fund transitional living centers/day treatment/community re-entry	3
Long term funding for survivors	2
Reimbursement sources for TBI	1
Resources to support comprehensive program	1
Retention of financial benefits	1
<b>Housing</b>	<b>85</b>
Affordable assisted living homes/options	17
Affordable housing options	29
Comprehensive residential programs	7
Group home	2
<b>Appendix 9</b>	
<b>Need/Gap</b>	<b>Number</b>
<b>Housing [continued]</b>	

Housing options for indigent/uninsured	4
Long term care options	5
More living arrangement options	1
Secure perimeter residential care	1
Skilled nursing home that takes MediCal	2
Supported living	7
Transitional living programs	10
<b>Information/Communication</b>	<b>25</b>
Available resources and how to access	9
Better communication	1
Central resource for services/information in the community	1
Computer links for information/referral	1
Data banks	1
Educational materials for families/caregivers	1
Funding awareness/accessibility	1
Information on resources for acute/sub acute hospitals/ other providers	3
Information on services resources	3
National organizations	1
Where to refer for long term care	1
Written material	1
Written material on resources for non English speaking populations	1
<b>Improved Infrastructure</b>	<b>129</b>
Advocacy	2
Better continuum of services	12
Better interface between DR and rehabilitation programs	1
Casefinding, needs identification and referrals for survivors	7
Central intake process	1
Children's programming/prevention and treatment	8
Choice and full inclusion in society	1
Comprehensive programs	1
Coordination of community agencies/services	4
Coordination of transitional living/re-integration resources	3
Department of Rehabilitation services	4
Designated trauma centers	1
Develop distinct TBI services	1
Earlier intervention with families	1
Easy accessible links to services and benefits	1
Expansion to serve large numbers of TBI survivors	5
Extended services to secure dignified future, especially Spanish speakers	1
Greater satisfaction with existing resources	3
Head trauma support network in all areas	1
Identification/treatment of mild brain injury	1
Identify and adopt best practice	1
Let agencies apply for funding for services that currently exist	1
Linkages to/collaboration with other services/agencies/providers	12
More state supported services	1

## Appendix 9

Need/Gap	Number
<b>Improved Infrastructure [continued]</b>	
Multi cultural understanding	2
Network of services/providers	6
Prevention programs as part of expanded Wellness Program	1

Program development	1
Programs to serve indigent/low income/MediCal only/no insurance	14
Referral network	5
Research	3
Services for all levels of injury	1
Support from public and government	1
Surveillance system	1
Timely, affordable services	1
Uniform community based options in throughout state	18
Working relationship with San Diego BIF	1
<b>Public/Professional Awareness/Education</b>	<b>25</b>
Department of Rehabilitation counselors trained and focused	4
Education of emergency room personnel	1
Education of medical staff/insurance companies regarding long term outcomes	5
Knowledge of community resources	3
Public/professional education/awareness	8
Staff training/awareness	4
<b>Replicate and/or Expand Model Programs</b>	<b>26</b>
Academic programs with trained staff for TBI	1
Caregiver Resources Center	3
Center for Independent Living	3
Community college brain injury programs	5
Enabler program at Fresno City College	1
Expand Stroke Activity Center to include TBI	1
Head Injury Services of Los Angeles	1
On Track through Mt. Diablo School District	1
Regional center system with funds for TBI	7
Santa Clara Brain Injured program	1
Systems in place that serve other populations	1
Vocational rehabilitation support to develop programs	1
<b>Service Needs</b>	<b>111</b>
Affordable long term resources/services	4
Assistive technology resources	3
Basic skills training	2
Behavioral programs/survivors/families	8
Cognitive rehabilitation resources	4
Dual diagnosis treatment for TBI and chemical dependence	1
Educational opportunities	2
Equipment	1
Emergency services	1
Exercise fitness programs	1
Expanded mental health and substance abuse services	2
Expanded services for severe behaviors	2

## Appendix 9

Need/Gap	Number
<b>Service Needs [continued]</b>	
In home rehab/other services	6
Legal services	2
Long term rehabilitation	6
Long term services/support and follow up	14
Mental health services	5
More service options for survivors funded by MediCal/Medicare/low income	9

Ongoing medical care	2
Post injury reintegration services	16
Program to help adapt to new selves and environments	2
Regular evaluation/adjustments for services	1
Respite	5
School reintegration	2
Services for chronic TBI	1
Services for non English speaking survivors	1
Support services for caregivers/elderly parents	7
Treatment of acute, severe head injuries	1
<b>Social/Recreation</b>	<b>10</b>
Drop in center for peer relationships with trained therapist	1
Recreation	5
Social opportunities	4
<b>Specialized Services</b>	<b>20</b>
Cognitive therapy	1
Neuropsychological	3
Neurosurgical/neurological	6
Nursing	1
On site workers to help with TARS/MediCal eligibility	1
Physicians panels	1
Service providers for non English language survivors	2
Speech/physical/occupational therapies	4
Sub acute/long term beds for psychiatric and TBI	1
<b>Support Groups</b>	<b>17</b>
Central website that lists all support groups with links to leaders	1
Counseling and support groups for parents/family members	1
Network of support groups throughout the state	2
Ongoing support groups for survivors and caretakers	9
Support group network	2
Support groups for children/teens of survivors	1
Support groups for family	2
<b>Training</b>	<b>2</b>
Caretaker training in languages other than English	1
Social security	1
<b>Transportation</b>	<b>27</b>
Available transportation	25
Driving evaluations	1
Heliport transportation	1
<b>Total Service Needs/Gaps</b>	<b>624</b>

## Provider Rating of Service Availability

County	Prevention		Emergency		Rehabilitation		Children/adolescents		Adults		Elementary Ed.	
	Providers	Average	Providers	Average	Providers	Average	Providers	Average	Providers	Average	Providers	Average
Alameda	4	1.0	4	3.0	4	2.8	3	2.0	4	1.8	4	1.8
Butte	5	1.6	5	2.7	5	1.8	5	1.6	5	1.6	4	1.8
Colusa	1	1.0	1	2.0	1	2.0	1	1.0	1	1.0	1	1
Contra Costa	2	2.0	2	3.0	2	2.0	2	1.0	2	1.0	2	1.5
Fresno	3	1.7	4	2.5	4	3.8	4	3.0	4	2.0	4	2
Glenn	1	1.0	1	2.0	1	3.0	1	1.0	1	1.0	1	1
Humboldt	6	1.7	6	2.8	6	2.3	6	2.3	6	2.3	6	1.8
Imperial	2	1.0	2	1.5	2	1.0	2	1.0	2	1.0	2	1
Inyo	1	2.0	1	2.0	1	2.0	1	2.0	1	2.0	1	2
Kern	3	2.0	3	3.0	3	3.0	3	1.3	3	1.3	3	1.7
Kings	1	1.0	1	3.0	1	2.0	1	1.0	1	1.0	1	2
Los Angeles	33	1.8	34	3.3	34	3.1	32	1.8	32	1.9	27	1.6
Marin	2	1.5	1	2.0	2	3.5	2	1.5	2	2.0	2	2.5
Mendicino	2	1.5	2	3.0	2	1.5	2	1.0	2	1.0	2	2
Merced	2	3.0	2	3.0	2	2.5	2	3.0	2	2.5	2	2.5
Monterey	3	2.3	3	3.7	3	3.0	3	3.0	3	2.3	3	2.3
Napa	3	1.3	3	4.3	3	3.3	3	1.3	3	1.3	2	1.5
Nevada	2	1.0	2	1.8	2	3.5	2	3.0	2	3.0	2	1.8
No City	1	1.0	1	4.0	1	4.0	1	3.0	1	4.0	1	3
Orange	21	2.2	21	3.4	21	3.1	21	2.0	21	2.6	20	2
Placer	3	2.0	3	3.3	3	3.7	2	2.5	2	2.5	1	2
Riverside	5	1.4	5	3.4	5	2.6	5	1.4	5	1.6	5	1.8
Sacramento	6	1.7	5	3.0	6	2.0	5	1.4	6	1.5	5	1.2
San Bernardino	5	2.0	6	3.7	6	2.7	6	2.7	6	2.7	4	2.3
San Diego	22	2.0	24	3.4	24	3.1	22	1.8	24	2.2	21	1.9
San Francisco	6	1.5	6	3.9	6	3.0	6	1.7	6	1.5	6	1.8
San Joaquin	2	1.0	2	2.5	2	1.0	2	1.0	2	1.0	2	1
San Mateo	2	1.5	3	2.0	2	1.5	3	2.0	3	2.0	3	1.7
Santa Barbara	2	2.5	2	3.0	2	2.0	1	4.0	2	2.0	1	3
Santa Clara	10	2.2	10	3.4	10	3.5	10	2.4	10	2.2	9	1.8
Santa Cruz	10	2.0	10	3.3	10	3.2	9	2.3	10	2.9	10	1.8
Solano	1	3.0	1	4.0	1	4.0	1	2.0	1	3.0	1	2
Sonoma	1	1.0	1	3.0	1	2.0	1	2.0	1	1.0	1	1
Stanislaus	3	2.3	3	2.7	3	1.7	3	2.0	3	2.7	3	1.7
Sutter	1	2.0	1	3.0	1	2.0	1	1.0	1	1.0	1	1
Tehama	1	3.0	1	4.0	1	4.0			1	3.0	1	4
Tulare	1	1.5	1	3.5	1	4.0	1	1.0	1	1.0	1	1.5
Ventura	5	2.2	5	3.2	5	3.2	5	2.8	5	3.0	5	2.4



## Provider Rating of Service Availability

County	Secondary Ed.		Vocational		Community Supports		Long-term Funding		Assisted living	
	Providers	Average	Providers	Average	Providers	Average	Providers	Average	Providers	Average
Alameda	4	1.8	4	1.3	4	1.5	4	1	4	1
Butte	4	1.3	5	1.4	5	1.4	5	1	5	1
Colusa	1	1	1	1	1	1	1	1	1	1
Contra Costa	2	1.5	2	1	2	1	2	1	2	1
Fresno	4	2	4	2.1	4	2.4	4	1.8	4	1.8
Glenn	1	1	1	1	1	1	1	1	1	1
Humboldt	6	1.8	6	2.3	6	2.1	6	1.3	6	1.3
Imperial	2	1	2	1	2	1	2	1.5	2	1.5
Inyo	1	2	1	2	1	2	1	2	1	2
Kern	3	1.7	3	2	3	2	3	2	3	1.7
Kings	1	1	1	1	1	1	1	1	1	1
Los Angeles	27	1.6	29	1.8	Appe	1.7	30	1.5	30	1.7
Marin	2	2.5	2	1.5	2	1.5	2	1.5	2	1.5
Mendicino	2	2	2	1	2	1	2	1	2	1.5
Merced	2	2.5	2	2.5	3	3	2	2.5	2	2.5
Monterey	3	2.3	3	2.3	3	2	3	2	3	2
Napa	2	1.5	3	2	3	1.7	3	1.3	2	1.3
Nevada	2	1.5	2	1.8	2	1.5	2	1	2	1
No City	1	3	1	2	1	2	1	3	1	2
Orange	20	2.1	21	2.2	21	2.4	21	1.5	21	2
Placer	1	2	1	3	2	2	1	3	1	2
Riverside	5	2	5	1.2	5	1.6	4	1.8	5	1.8
Sacramento	5	1.2	5	1.8	6	1.5	6	1.3	6	1.3
San Bernardino	4	2.3	5	1.8	5	2.2	6	1.7	5	1.8
San Diego	20	1.8	23	1.9	24	2.2	21	1.2	21	1.3
San Francisco	6	1.9	7	1.9	7	1.5	7	1.1	7	1.3
San Joaquin	2	1.5	2	1	2	1	2	1	2	1
San Mateo	3	1.7	3	1.3	3	2.2	3	1.5	3	2.2
Santa Barbara	2	2.5	2	1.5	2	1	2	1	2	1
Santa Clara	9	1.9	10	2.3	10	2.3	10	1.4	10	1.4
Santa Cruz	9	1.9	10	2.7	10	2.7	10	1.6	10	1.3
Solano	1	2	1	2	1	3	1	3	1	3
Sonoma	1	2	1	1	1	1	1	1	1	2
Stanislaus	3	2.3	3	2.3	3	2	2	1	3	1
Sutter	1	1	1	2	1	2	1	2	1	2
Tehama	1	4	1	3					1	3
Tulare	1	1.5	1	1.5	1	1.5	1	1.5	1	1
Ventura	5	2.4	5	2.6	5	2.4	4	2	4	1.8